

**ROLE OF SOCIAL SUPPORT ON ADHERENCE TO ANTIRETROVIRAL  
THERAPY AMONG PATIENTS ATTENDING AMPATH CLINIC AT MOI  
TEACHING AND REFERRAL HOSPITAL, ELDORET, KENYA**

**BY:**

**Kaguiri, C. Eunice**

**A THESIS SUBMITTED TO THE SCHOOL OF PUBLIC HEALTH,  
COLLEGE OF HEALTH SCIENCES IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE AWARD OF THE DEGREE OF MASTERS IN  
PUBLIC HEALTH**

**DEPARTMENT OF EPIDEMIOLOGY AND DISEASE CONTROL,**

**MOI UNIVERSITY**

**JUNE 2014**

## DECLARATION

### Candidate's Declaration

This thesis is my original work and has not been presented for a degree in any other University. No part of this thesis may be reproduced without prior permission from both the author and /or Moi University

Kaguiru, C. Eunice, \_\_\_\_\_

\_\_\_\_\_  
Reg. No. SPH/PGH/20/07      Signature

Date

### Declaration by the Supervisors:

This thesis is submitted with our approval as the University supervisors

Prof. E O. Were, \_\_\_\_\_

\_\_\_\_\_  
Professor,                      Signature

Date

Department of Reproductive Health,  
School of Medicine, College of Health Sciences  
Moi University.

Dr. J. B Baliddawa, \_\_\_\_\_

\_\_\_\_\_  
Senior Lecturer,              Signature

Date

Department of Behavioral Sciences and Ethics  
School of Medicine, College of Health sciences  
Moi University

**DEDICATION:**

This work is dedicated to my dear husband and children who always put a smile on my face and to all who have dedicated their time to fight against HIV/AIDS.

## ABSTRACT

**Introduction:** This study aimed at generating information on the level of adherence to Antiretroviral Therapy and the association between social support and adherence to ARVS among patients at the Academic Model for Providing Access to Health Care (AMPATH) clinic-Moi Teaching and Referral Hospital (MTRH) in Eldoret.

**Justification:** Poor adherence to ARVs can cause harm. Adherence is said to be optimum if the patient takes all pills in the correctly prescribed doses, at the right time and in the right way for at least 95% of the time. Social support has been recommended as one of the strategies of intervention to improve adherence. Social support has been introduced in most of health facilities but its effects on adherence remain undocumented in Kenya, hence the need for this study.

**Objectives:** 1. To estimate proportions of patients reporting optimum adherence to ARVs. 2. To identify the types of social support being utilized by AMPATH patients. 3. To determine the association between social support and adherence to ARVs

**Study Methods:** This was a cross sectional study in which a total of 299 patients were interviewed and 12 In-depth interviews conducted with care providers working at the AMPATH clinic at MTRH. Data was collected between January and March 2010.

**Study results:** The sample consisted of 108(36.1 %) males. The median age was 32 years (IQR 28-39). Optimum adherence was reported by 219(73.2%) of the participants. Those aged 25- 34 years were more likely to adhere compared to those aged below 25 years (Adjusted OR=3.36, 95% CI: 1.44 – 7.81, P = 0.005). Females were more likely to adhere (Adjusted OR=2.80, 95% CI: 1.45 – 5.38, P = 0.002). Most of the participants (184, 61.5%) reported to be members of support groups, 190(63.5%) reported to have disclosed their HIV status to their sexual partners and advice from health care providers was reported by all the participants. Reporting optimum adherence was positively associated with disclosure of HIV status to sexual partner (Adjusted OR= 2.43, 95% CI: 1.37 – 4.29 P value= 0.002), belonging to a support group (Adjusted OR=2.68, 95% CI: 1.51 – 4.76, P value = 0.001) and perceived support from children (Adjusted OR=2.90, 95% CI: 1.29 – 6.53, P value = 0.01).

**Conclusion & recommendation:** Belonging to a support group, disclosure to partner and perceived support from children was positively associated with optimum adherence. Patients should be encouraged to join support groups and also disclose their status to their spouses to enhance support from these members of the family.

## TABLE OF CONTENTS

DECLARATION .....	ii
DEDICATION:.....	iii
ABSTRACT.....	iv
TABLE OF CONTENTS.....	v
LIST OF TABLES .....	viii
LIST OF FIGURES .....	ix
ABBREVIATIONS .....	x
OPERATIONAL DEFINITIONS.....	xii
ACKNOWLEDGEMENT .....	xiii
CHAPTER ONE: .....	1
1.0 Introduction and background. ....	1
1.1 Problem statement.....	2
1.2 Research questions:.....	3
1.3 Justification: .....	3
1.4 Study Objectives .....	5
CHAPTER TWO: .....	6
LITERATURE REVIEW .....	6
2.0 HIV pandemic .....	6
2.1 ARV treatment .....	6
2.2 Adherence to ARVS .....	7
2.3 Measuring adherence .....	8
2.4 Factors affecting adherence to ARVS .....	10
2.4.1 Regimen characteristics.....	10
2.4.2 Patient related factors: .....	11
2.4.3 Provider-patient relationship .....	13
2.5 Social support and adherence.....	13
2.6 Measurements of social support.....	17
CHAPTER THREE .....	20
METHODOLOGY .....	20
3.0 Study setting: .....	20
3.1 Study design:.....	21
3.2 Sampling Procedure .....	21
3.2.1 Sample Size and Justification:.....	21

3.2.2 Sampling Technique and Procedures: .....	22
3.3 Data Collection: .....	23
3.3.1 Interviewer administered questionnaires: .....	23
3.3.2 Measuring adherence .....	23
3.3.3 Measuring perceived level of social support .....	25
3.3.4 Key Informant Interviews: .....	26
3.4 Eligibility criteria .....	26
3.4.1 Inclusion criteria .....	26
3.4.2 Exclusion criteria .....	28
3.5 Data management .....	28
3.5.1 Data quality checks .....	28
3.5.2 Data handling and cleaning: .....	28
3.5.3 Data analysis .....	29
3.5.4 Data presentation .....	30
3.5.5 Computation of analytic variables .....	30
3.6 Ethical considerations .....	32
CHAPTER FOUR .....	33
STUDY RESULTS .....	33
4.0 Demographics of participants .....	33
4.1 Level of adherence .....	34
4.2 Uptake of social support services/social integration .....	36
4.3 Demographic factors associated with adherence to ARVs among AMPATH patients .....	38
4.4 Association between social support and adherence to ARVs among AMPATH patients .....	40
CHAPTER FIVE: .....	44
Discussion .....	44
5.0 Level of adherence to HAART .....	44
5.1 Reasons for non-adherence to HAART .....	45
5.2 Determinants of adherence to HAART .....	46
5.3 Uptake of social support services .....	47
5.4 Association between social support and adherence to ARVs .....	48
5.5 Study limitations: .....	50
5.6 Conclusion .....	51

5.7 Recommendations .....	51
REFERENCES .....	52
APPENDICES: .....	58
Appendix I: Questionnaire: Interview with Patients.....	58
Appendix II: Questions for Key Informant Interviews.....	62
Appendix III: Consent Form.....	63
Appendix IV: Google Map of AMPATH Sites .....	65
Appendix V: Approval letter from IREC.....	66
Appendix VI: Permission letter from AMPATH-Research Office.....	67

**LIST OF TABLES**

Table 1: Distribution of sample size across the modules.....	22
Table 2: Computation of analytic variables .....	31
Table 3: Demographic characteristics of participants.....	33
Table 4: Prevalence of adherence .....	34
Table 5: Level of perceived social support .....	37
Table 6: Demographic factors associated with adherence to ARVs.....	38
Table 8: Association between social support and adherence to ARVS. ....	40
Table 9: Multivariate logistic regression on association between social support and adherence .....	41



**LIST OF FIGURES**

Figure 1: Reasons for non adherence to ARVS.....	35
Figure 2: Uptake of social support services.....	36
Figure 3: Google map of AMPATH sites.....	65

**ABBREVIATIONS**

AACTG	Adult AIDS Clinical Trials Group
AIDS	Acquired Immunodeficiency Syndrome
AMPATH	Academic Model for Providing Access to Health Care
ART	Antiretroviral Therapy/Treatment
ARV	Antiretroviral (drug)
ARVs	Antiretroviral drugs
B	Beta
BSSS	Berlin Social Support Scales
CD4	Cluster Differentiated cells
CBS	Central Bureau of Statistics
CI	Confidence Interval
Dr	Doctor
df	Degrees of Freedom
DD	Date
Exp B	Exponential Beta
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IREC	Institutional Research and Ethics Committee
IQR	Inter Quartile Range
KDHS	Kenya Demographic and Health Survey
KII	Key Informant Interview
KSH	Kenyan Shilling
KAIS	Kenya AIDS Indicator Survey
MB	Mega bytes
MEMS	Medication Event Monitoring System
MOH	Ministry of Health
MTRH	Moi Teaching and Referral Hospital
MM	Month
NACC	National AIDS Control Council
NASCOP	National AIDS and STI Program
OR	Odds Ratio
PMTCT	Prevention of Mother to Child Transmission
PLWHAs	People living with HIV/AIDS

P-VALUE	Probability Value
Prof	Professor
PGH	Post Graduate Health
Reg.	Registration number
SE	Standard Error
Sig	Level of significant
STI	Sexually Transmitted Infection
SPSS	Statistical Package for Social Scientists
SPH	School of Public Health
SOM	School of Medicine
T-TEST	Student's T test
UNAIDS	United Nations Program on HIV/AIDS
WHO	World Health Organization
YY	Year

## **OPERATIONAL DEFINITIONS**

**Adherence:** According to World Health Organization (WHO), it is the extent to which a person's behavior corresponds with agreed recommendations from a health care provider. Adherence to ARVs involves taking all pills in the correctly prescribed doses, at the right time, and in the right way. For this study, this was measured using self report whereby the clients were asked to report any missed doses, any doses taken without following special instructions and any doses taken without following schedule over the last 4 days.

**Social support:** Social support is the physical and emotional comfort given to people by their family, friends, co-workers and others. Social support can come in many different forms: Emotional, tangible and Informational Support. For this study, social support will encompass the following types of social support: support group membership and attendance, Human Immunodeficiency Virus (HIV) status disclosure, food supplements, amount of income and counseling services from the health care providers.

**Support groups:** These are groups often led by a trained person who shares information about the problem at hand. Other groups focus on support. They often include only people who have the same problem. These are called peer groups.

**Perceived support :** This is defined as the subjective judgment that family and friends would provide quality assistance with future stressors. People with high perceived-support believe that they can count on their family and friends to provide quality assistance during times of trouble. This assistance may include listening to the stressed person talk about troubles, expressing warmth and affection, offering advice or another way of looking at the problem.

## **ACKNOWLEDGEMENT**

I wish to thank my supervisors Prof. Edwin Were and Dr. J.B Baliddawa for their professional guidance through every step of developing this thesis. I also acknowledge Moi University, School of Public Health lecturers for facilitating the development of this thesis

I acknowledge the management of AMPATH for allowing the conduct of the research at the clinic.

I sincerely appreciate the financial and moral support provided by my husband.

Lastly I wish to express my sincere appreciation to the AMPATH patients and staff for their willingness to participate in this study.

## CHAPTER ONE:

### 1.0 Introduction and background.

Human Immunodeficiency Virus still remains a major public health problem in the world with an estimated 34.1 million people infected. The problem is especially more in Sub-Saharan Africa because approximately 69% of these people live in this part of the world. The estimated number of deaths due to AIDS related complications in 2011 was 1.7 million worldwide of which 70% occurred in sub-Saharan Africa. Kenya has a generalized HIV epidemic, with approximately 1.6 million people living with HIV<sup>(1)</sup>.

In recent years, the international donor community has invested tremendously in making access to Anti-retroviral therapy a reality for HIV-positive patients living in developing countries. By the end of 2011, antiretroviral therapy reached 8 million people and this has added approximately 14 million life-years in low and middle income countries. Out of the estimated 750,000 patients in need of ART in Kenya by end of 2011, approximately 538,983(72%) were on ARVs. It has also been shown that treatment retention is possible and can be achieved in Kenya with a total of 75% of adults and children known to have continued with the therapy beyond 12 months after initiation of ART by 2011.<sup>(2)</sup>

World Health Organization (WHO) recommendations on the use of antiretroviral therapy in resource-limited settings recognize the critical role of adherence in order to achieve clinical and programmatic success.<sup>(3)</sup> Adherence to ARV treatment regimen involves taking all pills in the correctly prescribed doses, at the right time, and in the right way. Good adherence is vital for achieving and maintaining maximal viral suppression and thus avoiding preventable opportunistic Infections. It's a key

determinant of success of ARV therapy. The best response to ART is seen when adherence is 100%. Levels of adherence below 95% have been associated with poor suppression of HIV viral load and a lower increase in CD4 count. It is therefore very important for HIV treatment programs to emphasize the importance of HIV treatment adherence to achieve positive treatment outcomes which includes suppression of HIV viral load, increase in Cluster Differential cells count (CD4) and avoiding development of resistant HIV strains<sup>(4)</sup>.

Challenges to sustaining high level of adherence to treatment include treatment related hunger, the burden of out of pocket expenses, lost wages, side effects, long waiting times at the treatment centers, lack of social support, fear of stigma and discrimination.<sup>(5)</sup>

Social support on the other hand means physical or emotional assistance given by family, friends, coworkers. It can be categorized into three types: Perceived support, Enacted support and Social integration<sup>(4)</sup> with an aim of ensuring sustained treatment of HIV infection. It is therefore essential that effective social support be an integral part of any HIV management/ treatment program. This study sought to determine the association between social support and adherence to ARVS among patients attending AMPATH clinic –MTRH.

### **1.1 Problem statement**

With the introduction of antiretroviral therapy among the HIV/AIDS patients, adherence to ARVs is a worldwide concern especially more in the resource constrained settings due to cost implications. The best response to ART is achieved when adherence is 100%. Poor adherence to ARVs leads to increase in viral load, low CD4 and development of resistant strains of the HIV. Improving long-term adherence

is complex and requires continuous support and monitoring. Prevalence of adherence in Africa is estimated at 77% <sup>(5)</sup>, which is higher compared to the industrialized settings but there is no room for complacency since adherence rates tend to deteriorate over time <sup>(6)</sup>. The Kenyan national guidelines on ARV treatment requires that psychosocial assessment of all patients be done to determine need for psychosocial support and appropriate referral to enhance their ability to adhere to antiretroviral therapy. Some clinical settings like AMPATH are providing opportunities for patients to get the support they need to adhere to treatment regimens <sup>(2)</sup>. Although social support has been studied generally, the uptake of social support services and its association with adherence to ARVs has not been studied.

The purpose of this study was to outline the different types of social support services that are utilized by patients on ARVs at AMPATH clinic and determine the association between social support and adherence to ARVs among these patients.

### **1.2 Research questions:**

1. What are the different types of social support services that are utilized by patients on ARVs attending AMPATH clinic at MTRH?
2. Is there association between social support and adherence to ART among patients attending AMPATH clinic at MTRH?

### **1.3 Justification:**

Although ARVs have dramatically prolonged and improved the quality of life of HIV-infected persons, there are threats to the sustainability of these gains. Adherence to medication has generally been documented to be challenging for everyone and long term treatment presents the most difficult challenges. This is due to reasons like side



effects and taking drugs over a long period. Adherence to antiretroviral therapy is critical to the successful care of patients with HIV/AIDS. On an individual level, adherence to care and treatment can mean the difference between life and death. On a population level, adherence to treatment can minimize the emergence of viral resistance and prevent therapeutic failure. Availability and accessibility of ARVs to members of the community who require them would be less beneficial if the required adherence levels are not achieved because this will lead to development of resistant strains of the HIV which will be more challenging to treat. Studies have demonstrated that the relationship between adherence to antiretroviral regimen and the probability of developing resistance is a bell shaped curve which means that low potential for resistance exists both with low levels (below 70%) and high levels (above 95%) of adherence. Suboptimal levels of between 70-95% are associated with the highest probability of developing resistance. <sup>(7)</sup> There is a big risk of trying to improve adherence from low levels to suboptimal levels because as one imagines that they are improving the life of the patients but in reality, the possibility of developing resistance is actually increasing. It is therefore very important to measure adherence to ART continuously so as to monitor and know when intervention is required.

Chronic conditions, HIV included are a major problem in the world. Attending to these conditions cannot be fully handled using the facility based support systems. Community based support systems that are effective need to be identified.

Social support has been recommended to improve adherence to ARVs but very few studies have been conducted in this part of the world to determine the association between social support services and adherence to ARVs. The study identified the different types of social support being utilized by the AMPATH patients. The study

also determined the association between social support and adherence to ARVs among these patients. The results provide information that would enable informed modification of process as regards social support systems to enhance optimum adherence among patients attending AMPATH clinic at MTRH and even other ART clinics especially within resource constrained settings. The results are especially useful to Health care providers and social workers in developing interventions aimed at improving adherence to ARVS.

## **1.4 Study Objectives**

### **1.4.1 General objective**

To determine the association between social support and adherence to ARVs among patients attending AMPATH clinic at MTRH.

### **1.4.2 Specific Objectives**

1. To estimate the proportion of patients reporting optimum adherence to ARVs at the AMPATH clinic at MTRH.
2. To outline the types of social support being utilized by the AMPATH patients and the level of perceived social support.
3. To assess the factors associated with adherence to ARVs among patients attending AMPATH clinic at MTRH.
4. To determine the association between different types of social support and adherence to ARVs among AMPATH patients.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.0 HIV pandemic**

The global AIDS epidemic seems to have stabilized with decreasing incidence since the late 1990s but still remains a major public health problem with an estimated 34 million people infected by the end of 2011. The Sub-Saharan Africa is more affected by the scourge where it is believed that 1 in every 20 adults (4.9%) is living with HIV and this amounts to some 23.5 million people currently living with HIV in this part of the world. <sup>(1)</sup>

Kenya has a generalized HIV epidemic with an estimated national adult HIV prevalence of 6.2% as of December 2011. Approximately 104,137 new infections were recorded in Kenya in 2011. During the past three years, critical HIV services have been scaled up. As a result, general awareness and knowledge of HIV transmission are nearly universal. In 2010, more than 5.7 million Kenyans underwent HIV testing, and 83% of those in need of treatment had access to it. <sup>(2)</sup> However, with an estimated 1.6 million people currently living with HIV, Kenya still contends with a serious AIDS epidemic and the fight is still on.

### **2.1 ARV treatment**

Since the advent of ARVs in 1995, HIV-related mortality and morbidity rates have reduced substantially. Antiretroviral therapy has saved approximately 14 million life years in middle and low income countries since 1995 including 9 million in the sub-Saharan Africa. <sup>(1)</sup>

The therapy uses combinations of drugs and can inhibit the spread of HIV within a person's body. For some HIV-infected persons, ARVs have been an effective way to prevent the onset of AIDS and prolong life. The biological and clinical goals of treatment have been defined as the suppression of viral replication, restoration of the immune response, a halt in the progression of disease, increased survival rates, reduced morbidity and a better quality of life. <sup>(8)</sup>

Guidelines for antiretroviral drug therapy in Kenya have been developed and are aimed at making ARVs accessible to all who can benefit from such it. Though this care is difficult and expensive, ARVs are now more widely available in Kenya. <sup>(9)</sup> By the end of 2011, approximately 539,000 out of 750,000 Kenyans in need of ARV treatment according to WHO 2010 guidelines were on treatment and the others were waiting to start treatment<sup>(1)</sup>.

## **2.2 Adherence to ARVS**

According to WHO, Adherence to ARV treatment regimen involves taking all pills in the correctly prescribed doses, at the right time, and in the right way. <sup>(3)</sup>

Adherence to combination ARVs has a strong impact on virologic response and emergence of viral resistance. It is particularly challenging because of the need to achieve very high (at least 95%) levels of adherence to prevent treatment failure and the generation of ARV resistant virus. Levels of adherence below 95% have also been associated with poor suppression of HIV viral load and a lower increase in CD4 count <sup>(7)</sup>

In 2000, when research on adherence was initiated, Chesney reported a strong correlation between the level of medication adherence and the percentage of patients

without detectable level of the virus. When patients achieved less than 80% adherence, 87% of them had detectable virus. When adherence was between 80% and 90%, treatment failure occurred in 47% of the patients; and when adherence was more than 95%, detectable virus occurred in only 10% of patients. Although the sample size was small, it did underline the importance of high levels of adherence.<sup>(10)</sup>

### **2.3 Measuring adherence**

It is important to monitor patient's adherence to ARVS so as to know when intervention is needed. Generally, there are methodological difficulties of measuring adherence. There is no gold standard of adherence assessment. The key to measuring adherence accurately is to ensure that respondents do not feel threatened when reporting in one way or another non-adherent event. Some of the essential components of the process are that it should be non-judgmental, non-confrontational and collaborative. The patient should have permission to admit less than perfect adherence.<sup>(10)</sup>

One of the commonly used measurements of adherence is the patients' self-reports on how often they take their medication. It involves interviewing the patients on how they have been taking their pills. Some of the limitations include the fact that patients may forget especially if it is over a long period of time. They may also say whatever they think their physician wants to hear<sup>(11)</sup> regardless of their actual adherence behavior but patients will rarely say their adherence is poor when it is not.<sup>(12)</sup> A patient's admission of poor adherence is a specific, but insensitive, marker of non-adherence. Time frame should be considered to improve recall. Despite the limitations of self-report, its association with viral response outcome has been demonstrated and it is also a cheap method to use<sup>(13)</sup>.

Use of diaries to record any missed dose is another method because patients often have difficulty remembering missed medications taken more than a couple of days ago. Some of the limitations of this method include the fact that most patients do not complete diaries and that when they do, they may fill in the information immediately before a clinic visit and most of them may not return their diaries to the clinic as instructed.<sup>(14)</sup>

Pill Counts entails having a health care provider count pills remaining in a bottle to be able to estimate the patient's adherence. The advantage of pill counts is that they are not affected by subjective patient responses. However, pill counts have limitations because many patients may forget to bring their pill bottles to the clinic when instructed, some participants may be well informed to remove or throw some of the pills from the bottles just before attending the clinic. Performing pill counts is also time-consuming. In addition, patients may find pill counts intrusive and this may harm the relationship between the patient and the health care provider<sup>(14)</sup>.

Electronic Devices such as Medication Event Monitoring System (MEMS) is whereby bottles have caps which have been fitted with electronic chips that register every time the bottle is opened and closed. This is the most sophisticated method available for measuring adherence. The health care providers can then download information from the electronic device and know the exact time the pill bottle was opened. Some of its limitations include the fact that a patient could open the bottle and not swallow the pill and MEMS are also expensive hence limiting their clinical utility. Well-known studies employing these devices have provided excellent data that quantify the relationship between medication dosing and adherence.<sup>(15)</sup>

Laboratory Markers are the biologic changes induced by antiretroviral medication and can be used to measure adherence. For example, zidovudine and stavudine raise the mean corpuscular volume,<sup>(16)</sup> didanosine alters urinary uric acid levels,<sup>(17)</sup> and indinavir raises bilirubin levels.<sup>(18)</sup> While these data provide objective measurements and have been used as markers of adherence, such changes are only marginally sensitive and specific markers of medication adherence and give no information about individual patterns of missed doses. In addition, results may be confounded by pharmacokinetic factors, such as poor drug absorption or drug-drug interactions, which may mimic poor adherence. Drug levels of antiretroviral medications have been used to gauge adherence in the research setting,<sup>(19)</sup> but they reflect only recent adherence (i.e., within 24 hours). Other limitations include patients who are well informed taking medications only immediately before scheduled blood draws and lack of commercial availability of the needed assays.<sup>(20)</sup>

## **2.4 Factors affecting adherence to ARVS**

Three types of factors that have been associated with adherence have been identified, these include; Regimen characteristics, patient characteristics, and the relationship between the provider and patient<sup>(21)</sup>.

### **2.4.1 Regimen characteristics**

#### **Pill burden**

According to W.H.O, 2003, higher pill burden has been associated with lower adherence.<sup>(21)</sup> A study in South Africa found that three times a day therapy was the strongest predictor of poor adherence. In addition to dosage, the patients are expected to take their pills on schedule and also follow instructions<sup>(22)</sup>.

### **Side effects and Toxicity**

This is another factor which has been associated with low adherence. Some of the side effects include nausea, anemia, skin rashes, dizziness and lack of appetite <sup>(23)</sup>. According to a study done in Botswana study over half of the respondents reported experiencing one side effect or another and this was associated with non-adherence in the population <sup>(24)</sup>.

#### **2.4.2 Patient related factors:**

##### **Beliefs**

Beliefs can affect adherence both positively and negatively. Research shows that a patient belief in the efficacy of ARVs motivates them to take the drugs as required due to the faith that they develop in the drugs <sup>(5)</sup>. Other people believe that they take drugs only when they are sick. <sup>(25)</sup>

##### **Knowledge and information**

Available evidence suggests that a good level of understanding about HIV/AIDS and awareness of the consequences of non-adherence are associated with good adherence. It is, therefore, expected that misinformation and misconceptions about the treatment would compromise an individual's ability to adhere. Indeed cases of lacking correct information are abound, leading to some PLWAS sharing medications or not taking them correctly <sup>(24)</sup>

##### **Alcohol and substance use**

Studies done in Botswana and South Africa have shown that there is association between alcohol use and non-adherence. When a patient is under the influence of alcohol, then most of the time they will forget to take their medication. <sup>(25, 26)</sup>



### **Cost of medication.**

Cost of medication has been associated with adherence. According to a study done by in Botswana, respondents who identified the cost of ARVs to be a major problem were less likely to adhere than those who did not identify cost as a barrier. These costs include the actual cost of the drug; financial constraints may lead to selling of drugs which they may have acquired free of charge so that they can buy other important things like food. Other types of cost include registration cost and fare to the clinic. <sup>(24)</sup>

### **Stigma and Disclosure**

Until now, people are still stigmatized because of HIV/AIDS. According to UNAIDS, some of these actions include discrimination, avoidance, ridicule and harassment. According to a study done among the youths, half of the respondents reported to have skipped doses because they feared family or friends would discover their status. Stigma affects treatment at different levels including communication with medical providers and adherence to medication among other levels <sup>(23)</sup>.

Many studies have reported non-disclosure to be high among people living with HIV/AIDS. According to a study done in Botswana found that 69% had not disclosed their HIV status to their families and 94% had not disclosed to the society. This is because of the fear of stigmatization. <sup>(23)</sup> This results in poor adherence because the patient cannot take drugs in the open. They may have to wait for their partners to go and sleep.

### **Food and Hunger**

Patients have reported lack of food as one of the main reasons for poor adherence. This is especially for drugs with special instructions. Lack of food is due to low social economic status. <sup>(25)</sup>

### **2.4.3 Provider-patient relationship**

Research has shown that there is association between adherence and the relation between the patient and the provider. <sup>(27)</sup>. Because of the sensitivity of ARV treatment, It's is encouraged that there should be open discussion with patient and that the health care provider should be non-judgmental and non-confrontational so that the patient can open up and discuss their challenges. By doing this, the health care provider is able to establish readiness , tailor the regimen frequency and timing, prepare the patient, including addressing cultural beliefs, anticipate and manage side effects, assess adherence easily and promote the patient's trust in the provider.

Other reported facilitators of adherence include self-efficacy, social support, an effective adherence counseling program, perceived benefits of the medication, and a desire to stay alive for the sake of others. Efforts to improve the level of adherence require a collaborative approach involving the patient, the community, health workers and policymakers, and a focus on ways of addressing environmental and structural constraints. <sup>(5)</sup>

Characteristics associated with improving and lowering adherence differ and should be considered in developing interventions to enhance adherence and optimize effective therapies. <sup>(7)</sup>

### **2.5 Social support and adherence**

Social support is the physical and emotional comfort given by family, friends, co-workers and others. It is available to a person or community through social ties to other people, groups, or communities. Social support can come in many different forms: Emotional Support, Informational Support which includes sharing points of view, personal feedback, practical help or instrumental support. <sup>(28)</sup>

Social support consists of three types of support which are perceived support, enacted support and social integration. Perceived support is subjective judgment that family and friends would provide quality assistance even in the future. Enacted support reflects the same kind of assistance as perceived support but emphasizes more on specific supportive actions. Social integration refers to the number or range of different types of social relations such as marital status, siblings and membership organizations like churches, mosques or even temples. <sup>(29)</sup>

Receiving support gives meaning to individuals' lives because of motivating them to feel obligated to give in return and to be attached to their ties. Being embedded in a positive social world might be more powerful in influencing people to adhere to their obligations <sup>(30)</sup>.

To get the full picture of how an individual's social situation is characterized, it is valuable to know about one's need for support. Some people feel better when they can master challenges alone, without help from others, and resort to outside assistance only in the worst case. Others feel more dependent and express a stronger need for support. <sup>(31)</sup>

Although HIV is thought to impact a single person, the effects extend to the family, communities and significant others <sup>(32)</sup>. Social support affects those infected with HIV in many ways including treatment adherence by reminding the patient to take medications and offer emotional support when needed. Greater support has been associated with improved medication adherence <sup>(33)</sup>. Increased support is associated with reduced substance use and sexual risk taking, lower viral load and higher CD4+ cell count <sup>(34)</sup>. Social support is indirectly related to adherence through its relationship with self-efficacy <sup>(35)</sup>. Social support can also be negatively related to health especially

in cases where interacting with others leads to feelings of stigma and alienation. It is also linked to mood disturbance in people who are HIV-positive<sup>(36)</sup>.

Social support, either from a health care professional or within one's personal environment, has been found to be quite successful in improving and maintaining high levels of adherence to medical recommendations. Other elements of social support that increase adherence include perceived support from the provider, patient satisfaction with the medical visit, and the support of family members in the home environment.<sup>(37)</sup>

Social support may play a small but potentially important role in helping HIV-positive people adhere to the complicated schedules for taking their drug to control the virus that causes AIDS.<sup>(38)</sup>

Social support is based on the kind of relationships and interactions that provide individuals with assistance or feelings of attachment. Generally, the availability of social support is critical for good adherence to ART. Children have been reported to be among the main providers of social support, with older (primary or secondary school age) children taking a leading role in reminding the parent (often their mother) of pill times. For those in stable relationships, the availability of social support from the partner is determined by whether that partner had tested and, if so, whether they have accepted their status<sup>(37)</sup>. If ARV users do not disclose their HIV positive status it may affect adherence in different ways including the fact that it may lead to patients taking their ARV medicines secretly and irregularly.<sup>(39)</sup>

Other examples of social support interventions include the reimbursement of hospital bills for needy people following a social worker's assessment, peer education schemes

and advocacy training, provision of food support especially to patients who are malnourished, clothing for very sick patients and special counseling.

Additional social support interventions are provided at different points by social workers who conduct home visits and by family members who are educated in family care. Psychological, spiritual, and educational support (individual, group, couple, family, and community counseling and education) particularly through peer support and group activities for people living with HIV/AIDS.<sup>(40)</sup>

A positive effect on adherence has been demonstrated when both members of a couple are educated on the importance of social support thus enhancing HAART adherence.<sup>(41)</sup>

Brief interventions have been proven successful in maintaining adherence but longer sessions or more rigorous interventions appear to be necessary to improve adherence in non-adherent patients<sup>(32)</sup>.

Social support appears to work best when offered in the clinical setting through the clinical care team. In fact, the single strongest and most consistent variable affecting adherence is the setting in which support is offered.<sup>(42)</sup>

It has been documented that a medical care setting helps staff identify and address patient problems with adherence quickly and effectively, because it allows easy contact and case conferencing among various members of the clinical staff. More important, medical care settings have more tools for managing side effects than non-clinical settings do. Clinicians can quickly adjust regimens to fit a client's lifestyle or address other problems such as side effects. When patients' regimens can be continually adjusted to be more effective and workable, the chance of adherence

success has been found to increase. As a result, doctors, nurses, and other clinical care staff seem best situated to offer adherence support. <sup>(33)</sup> What works in Kenya has not been documented.

## **2.6 Measurements of social support**

Social support can be assessed in a sophisticated manner, but researchers usually choose a straightforward approaches including: Perceived support measures are the most commonly used measures of social support. Among the most common instruments are the Berlin Social support scales <sup>(43)</sup>, Interpersonal Support Evaluation List and the Social Provisions Scale and the Social Provisions Scale <sup>(44)</sup>. The construct validity of measures of perceived support is extensive hence the measures correlate with a wide range of other measures of relationship perceptions. Indeed, measures of perceived support are related to generic relationship satisfaction, intimacy, low levels of conflict, and secure attachment styles Perceived support is positively related to mental self-esteem, perception of personal control, extraversion, positive affect and social skills. To maximize the extent to which perceived support measures reflect personal relationships and not respondent personality, social support should be assessed separately for each of the most important relationships, and these scales should be treated separately rather than summed across different relationship partners.

<sup>(45)</sup>

Enacted support involves behaviors/practices that would reinforce adherence e.g. reminders about when to take medication or attend scheduled clinic appointments. Measures of enacted support typically ask respondents to estimate the frequency with which they have received specific supportive behaviors/practices (or simply whether or not they have received the behaviors/practices). The most commonly used scale of

this kind is the Inventory of Socially Supportive Behaviors. Enacted support does not seem to be related as strongly or as consistently to the same kinds of positive relationship and personal characteristics, as is perceived support<sup>(45)</sup>.

Measures of social integration typically count the total number of relationships, the number of different types of relationships, frequency of contact with relationship partners, or the number of roles that respondent has<sup>(45)</sup>. These relationships include marital status, number of children, and other relatives that are close, close friends, belonging to a church or religious group, attending class/school, employment status, and belonging to support groups among others.

The most common demographic indicator considered is marital status in order to establish relationships between social integration and health.<sup>(31)</sup> A more comprehensive way to assess these constructs is to include the number of roles one assumes in the family and in organizations, such as church, as well as the frequency of contact to other members of such groups. Duration of contacts and degree of reciprocity are also important. A social network represents a web of relationships that encircles an individual together with network characteristics, such as range or size (number of members), density (degree of interconnection), or (extent of closeness such as kin, workplace, neighborhood), and homogeneity (similarity of members).<sup>(31)</sup>

The choice of instrument/scale or variables to use to measure social support depends on what the researcher want to measure, the internal consistency and also validity of the instrument.

From the literature, it's clear that social support can affect adherence to ARVS either positively or negatively, there is scanty information on how the different types of

social support affect adherence rates especially in Kenya and Sub-Saharan Africa for that matter. The aim of this study was to explore into the status of adherence to ARVS among patients attending AMPATH clinic, their utilization of social support services on offer and also assess the association between social support and adherence among these patients.



## CHAPTER THREE

### METHODOLOGY

#### 3.0 Study setting:

AMPATH is currently one of Kenya's largest public-sector ventures providing comprehensive HIV-prevention and treatment services. It has 71 satellite clinics located in several parts of Western Kenya. AMPATH has structured its patient care programmes to simultaneously serve as a laboratory for HIV-related teaching and research.

AMPATH adopts a comprehensive care approach that combines HIV prevention, treatment and care as well as research of HIV/AIDS in both urban and rural settings. The MTRH AMPATH clinic offers several HIV prevention and care services including Prevention of Mother to Child Transmission of HIV (PMTCT), Community education, treatment and care, research, HAART Health Initiative Incorporating Farming, Physician Training in HIV Management, Psychological support and outreach services. The Indiana University and World Food Program are also collaborating in providing nutritional support to food insecure outpatients who lack access to sufficient food. The distribution is to all household members of the targeted patients. The AMPATH Support Network was in place at the time of the study and over 9000 PLWHAs have enrolled.

AMPATH currently has over 150,000 patients, 88,000 of whom are on ARVs (AMPATH registry). All patients at the MTRH AMPATH clinic are seen in 4 modules. Three of these modules serve adults while one serves children. Apart from the children module, the adult patients are registered at other modules in a manner that

allows modules to have similar workload. The study participants were sampled from these three modules

### **3.1 Study design:**

This study was primarily quantitative, but qualitative data was collected to supplement the quantitative data collected, by generating in-depth information on how professionals in different AMPATH sections thought about social support and its effects on adherence to ART among the AMPATH patients. A cross sectional study was conducted. In this design, the questionnaires were administered to 299 participants in order to capture both the social support (exposure) and the adherence behavior (outcome) simultaneously. This study design enabled the researcher get a snap shot of how the two concepts are related with use of minimal resources available. Considering the time available for this exercise, this was the most feasible study design.

### **3.2 Sampling Procedure**

#### **3.2.1 Sample Size and Justification:**

In calculating the sample size for this study, the proportion of HIV positive patients on ARVs at AMPATH clinic- MTRH reporting perfect (95%) adherence during the first year was considered in order to meet the sample size requirements for the study objectives.

The sample size calculation was based on the Fischer's formula

$$N = \frac{z^2 pq}{D^2}$$

Where:  $z = 1.96$  (95% Confidence)

$p = 0.77$  (Proportion of HIV positive patients on ARVS at AMPATH clinic- MTRH reporting perfect (95%) adherence during the first year on ARVs. )<sup>(46)</sup>

$q = 1-p$

$D = 0.05$  (alpha error)

The sample size was 272

Considering the time and other resources available, an additional 27 participants were interviewed. The intention was to allow for a minimum of 272 participants with complete data assuming that approximately 10% of the sample would have missing data. It was however possible to obtain complete data for all the 299 selected participants.

### 3.2.2 Sampling Technique and Procedures:

Multistage sampling method was used in which the 3 modules constituted stratum/groups from which samples of study participants were drawn for interview.

The 3 modules at AMPATH MTRH were stratified such that each module represented a stratum that accounted for part of the sample (Table 1).

**Table 1: Distribution of sample size across the modules**

Number of clients on ARVs at AMPATH-MTRH (N=8533)	Module 1		Module 2		Module 3	
	N	%	N	%	N	%
	3523	41.2%	2467	28.9%	2543	29.9%
Sample size (N=272)	41.2% x 299 =123		28.9% x 299 =87		29.9% x 299 =89	

Participants who went to each module were selected for interviewing using systematic sampling method. In order to attain sample size of 299 participants from all the modules, the sampling interval were attained through dividing 8, 533 by 299 which

gave 28 and this meant that every 28<sup>th</sup> client was interviewed. The first client to be interviewed was randomly selected among the first 28 clients after recruitment started in each of the 3 modules. For participants who were not eligible or did not give consent, the next participant was interviewed.

Purposive sampling was used in determining the 12 subjects for Key Informant Interviews to have a representation of 4 clinicians, 4 adherence counselors and 4 community outreach workers.

### **3.3 Data Collection:**

Quantitative data was collected by use of a questionnaire, while qualitative data was collected using the Key Informant interview guide.

#### **3.3.1 Interviewer administered questionnaires:**

A total of 299 participants were interviewed. The research assistants administered the consent form to the potential participants explaining the risks and benefits of participating in the study before they consented to participate. Using the set of questions in the interviewer-administered questionnaire, the research assistants raised questions to the participants and responses recorded appropriately. The questionnaire contained both closed ended and open ended questions arranged into sections each of which was targeting a specific variable. Each session lasted for an average of 20 minutes. The interview was conducted in a quiet room within the clinic sites.

#### **3.3.2 Measuring adherence**

Adherence to HAART was measured by self-report using structured interview questions. This can be subject to overestimation as patients tend to overstate their adherence to treatment; this was however catered for by the fact that the interviews

were conducted by the research team and not the health care providers. The study participants were assured that their names will not be linked to their answers in whichever way. Even so, measuring adherence using patients' self-report can be easily replicated in most resource-limited settings including Kenya making it a good measure for comparison. The Adult AIDS Clinical Trials Group (AACTG) adherence instrument was used for this exercise. The instrument consists of nine questions that assess adherence from the previous 1-4 days, within the past week, prior to the interview. The instrument also assesses reasons for non-adherence.<sup>(47)</sup> This instrument has been validated in resource-limited settings.<sup>(48, 49)</sup>

Dose adherence was assessed by asking participants to report on how many days they had missed taking all their doses during the past 4 days. Dose non-adherence was defined as having missed at least one dose during the past 4 days. Adherence to scheduling was measured by the question "Most anti-HIV medications need to be taken on a schedule, such as '2 times a day' or '3 times a day' or 'every 8 hours.' The participants were asked to report how closely they followed their specific schedule over the last 4 days using a 5-point Likert scale, ranging from "never" to "all the time." Schedule non-adherence was defined as not following the schedule "all the time" in the past 4 days. Adherence to dietary instructions was measured by first asking "Do any of your anti-HIV medications have special food instructions, such as 'take with food' or 'on an empty stomach' or 'with plenty of fluids'?" If the response was "yes," participants were asked to rate how often they had followed dietary instructions over the last 4 days using a 5-point Likert scale, ranging from never" to "all the time." Dietary instructions non-adherence was defined as not having followed special instructions "all the time" over the last 4 days.

### **3.3.3 Measuring perceived level of social support**

This was measured using the Berlin Social Support Scales to measure the dimension of perceived social support. It is a validated instrument designed to assess perceptions about support from family, friends and a significant other. The BSSS scale was developed to assess quantity, type, and function of social support in general and in stressful circumstances and to investigate dyadic support interaction in stressful situations. The scales were developed and validated with an adult population of cancer patients. They can be used across different clinical and healthy adult populations. The instrument can be used for cross-sectional, longitudinal, experimental studies, clinical counseling and training. The internal consistency of Perceived Social Support (8 items): Cronbach's alpha = .83. The Validity of this instrument has also been demonstrated. The simplicity and shortness facilitates flexible use according to the particular assessment needs without compromising on reliability and validity. The items are easy to understand, the answering format is the same across all subscales. The BSSS is also suitable for repeated measurement. The scales may be applied in conjunction or separately. The main weakness of this instrument is that it is susceptible to distortion of measurement due to social desirability which is a typical problem in social support research <sup>(50)</sup>. The instrument was administered by people who were not linked in any way to health provision for the respondents and the respondents were assured that the information was not going to be linked to their names in any way or affect the services provided to them. One of the three subscales, i.e., perceived support, was used for this study. The subscale comprises items of emotional

and instrumental support; adding up all the items yielded the overall score for perceived support.

The answering format was such that participants indicated their agreement with the statements on a four-point Likert-type scale. Scale scores were obtained by adding up item responses (sum scores). Based on the sum of scores, two categories were built: “perceived support from support providers” and “no perceived support from the support providers” High scores indicated perceived support and low scores indicated no perceived support from the providers. The cut of mark for categorization was set at the upper quartile so that those who scored less than 24 out of total 32 were categorized as no perceived support from the provider and those who scored 24 and above were categorized otherwise.

### **3.3.4 Key Informant Interviews:**

12 In-depth Interviews were conducted in order to generate in-depth information about Social support services at AMPATH and how this affects adherence to ARVs among AMPATH patients. An interview guide containing open ended questions was used. KIIs were administered to 4 clinicians, 4 adherence counselors and 4 outreach workers. In a key informant interview, questions were posed from an interview guide by a research assistant. The interview sessions were recorded by the research assistant during the interview. The sessions lasted between 45 minutes and one hour.

## **3.4 Eligibility criteria**

### **3.4.1 Inclusion criteria**

- Were PLWHA on ART registered at the AMPATH clinic, MTRH
- Must have been on ARVs for at least 3 months.

- Respondents were willing and consented to participate.
- Above 18 years of age.



### 3.4.2 Exclusion criteria

- Those who did not meet the above criteria were excluded from the study.

## 3.5 Data management

### 3.5.1 Data quality checks

For reliability and validity of the data collected; training of the research team was done by the study investigator on both the study and the tools. Standardized tools were used in data collection. Analysis and reporting was done by the researcher. A pilot study was carried out at the AMPATH clinic- Mosoriot Health centre. The main aim of this was to pre-test the tools before actual use to establish their accuracy in generation of required information. The tools were reviewed and adjusted accordingly.

### 3.5.2 Data handling and cleaning:

**Quantitative data:** Interviewers submitted completed tools to the investigator at the end of each working day. A data base was developed from the questionnaire using the Statistical package for Social Scientists (SPSS) program; the Data were entered into the database and both the hard and soft copies are kept under lock and key for the purposes of confidentiality

**Qualitative data:** Audiotapes were transcribed in Microsoft Word by a transcriptionist fluent in languages used for the interview which was mainly English. Final transcripts for analysis were in English. To protect participant confidentiality, no names were transcribed in the final analysis of audiotapes. All tapes and hard copies of the translation and transcriptions are stored in a locked cabinet that only the analysts could access. All consent forms are archived under lock and key by the study

investigator. Tapes and transcriptions will be destroyed five years after final analyses of the data.

### **3.5.3 Data analysis**

Univariate analysis involved frequencies for demographics, uptake of social support services/social integration, computing the proportion of patients reporting optimum adherence rates and the level of perceived social support from different members of the society. At the bivariate level, Cross tabulation of adherence (dependent variable) against socio demographics and uptake of social support services (independent variables) was done this was in crude odds ratios, 95% confidence intervals and the corresponding p values. For multivariate analysis, the independent variables that had p value of  $<0.2$  at bivariate level of analysis were entered into a logistic regression model with adherence as the dependent variable, this was to test for the possibility that unadjusted association at bivariate level was due to confounding or effect modification. Final model results are reported in adjusted odds ratios with 95% confidence intervals and the corresponding p values.

### **Qualitative data**

From the Key Informant Interview transcribed data, summaries were drawn based on the major themes discussed during the In-depth Interviews. In the final analysis, a matrix was prepared from the transcriptions to get the main themes, concepts and ideas of discussion. Conclusions were then drawn as shown in the results and discussion sections of this document.

#### **3.5.4 Data presentation.**

Data is presented in tables and charts to show frequencies and associations, put together in form of a report. Information generated has been discussed in the report. For qualitative data, a summary of information generated by construct and illustrative quotes are presented in the results and discussion sections of report.

#### **3.5.5 Computation of analytic variables**

The table below shows how the analytic variables were computed

**Table 2: computation of analytic variables**

<b>Variable name</b>	<b>Operational definition</b>	<b>Categorization</b>
<b>Dependent variable</b>		
Adherence	One was said to have perfect adherence if they took “all” the pills over the last four days, followed the schedule “always” over the last four days and followed special instructions “always” over the last four days	Dichotomized into those who reported perfect adherence and those who did not
<b>Independent variables</b>		
Age	The number of years between the date of birth of the participant and the date of interview	Categorized into 5 classes namely ‘Below 25’, ‘25-34’, ‘35-44’, ‘45-54’, ‘55 and above’.
Sex	This is the gender of the participant	Dichotomized into ‘Males’ and ‘Females’
Level of education	The highest level of education the participant has achieved	Categorized into ‘primary’, ‘Secondary’ and ‘Tertiary’
Marital status	This referred to the current marital status of the participant	Categorized into ‘Single’, ‘Married’, ‘Divorced/separated’, ‘Windowed’
religion	This refers to the religion of the participants	Categorized into ‘Christians’ and ‘Muslims’
No. of children	No of children born of the participant	Categorized into ‘none’, ‘1-2’, ‘3-4’, ‘5 and above’
Main source of income	The main source of income of the participant	Categorized into ‘Formal’, ‘Informal’ and ‘None’
Support group membership	Participants were asked if they were members of the support groups	Dichotomized into ‘Yes’ and ‘No’
Support group attendance	Participants were asked if they attended support group meetings	Dichotomized into ‘Yes’ and ‘No’
Disclosure to partner	The participants were asked if they had disclosed their status to their sexual partners	Dichotomized into ‘Yes’ and ‘No’
Disclosure to other people	The participants were asked if they had disclosed their status to anybody else apart from the sexual partners	Dichotomized into ‘Yes’ and ‘No’
Food supplements	Participants were asked if they received food portions from the clinic	Dichotomized into ‘Yes’ and ‘No’
Advice fro health care provider	Participants asked if they were given advice by their health care provider	Dichotomized into ‘Yes’ and ‘No’
Perceived support	8 questions were administered each with a likert scale of 1 to 4. A total score was computed for each participant.	Dichotomized into ‘perceived support’ and ‘no perceived support’ based on their score. The cut off was set at the upper quartile.

### **3.6 Ethical considerations**

Information given by the respondents was kept confidential. Approval of the proposal was sought before implementation from Institutional Research Ethics Committee (IREC) of Moi University SPH, SOM and MTRH. The document was reviewed by IREC reviewers and approved for implementation.

Permission to do the study was also sought from AMPATH through the AMPATH research office.

The participants were given thorough explanation of the purpose for the study, risks and benefits for participating and also the voluntary nature of participating in the study.

**Respect of persons:** Informed consent was sought from each of the respondents of questionnaires and the KIIs prior to participation in the study. Those who declined to participate were not discriminated in any way and their decisions were respected. Names of the participants were not in any way produced in analyzed information, and raw data is confidentially kept under key and lock, and is only accessible to study staff. A consent form was used to document this.

**Beneficence:** There was no monetary benefit to the individual study participants. However, information generated will be useful in terms of decision making process as regards social support systems.

**Justice:** The sampling methodology that was used gave participants equal chance of participation in the study.

## CHAPTER FOUR

### STUDY RESULTS

#### 4.0 Demographics of participants.

**Table 3: Demographic characteristics of Participants**

Variable	Group	frequency	percent
Age in Years	Below 25 years	36	12.0
	25-34	138	46.2
	35-44	78	26.1
	45-54	36	12.0
	55 and above	11	3.7
Sex distribution	Male	108	36.1
	Female	191	63.9
Level of education	Primary	105	35.1
	Secondary	161	53.9
	Tertiary	33	11.0
Marital status	Single	53	17.7
	Married	172	57.5
	Separated/divorced	45	15.1
	Widowed	29	9.7
	Religion	Christians	287
Parity	Muslim	12	4.0
	None	34	11.4
Main source of income	1-2	128	42.7
	3-4	109	36.5
	5 and above	28	9.4
	Formal	56	18.7
Alcohol intake	Informal	155	51.9
	None	88	29.4
Alcohol intake	Yes	79	26.4
	No	220	73.6

Participants were aged between 18 and 62 years and the mean age was 34.1(SD=9.01 years). The median age was 32.0 (IQR 28-39). Most of the participants (138, 46.2%) were aged between 25 and 34 years. The highest proportion (191, 63.9%) was female. Slightly above half of the participants (161, 53.8%) had completed secondary education, 35.1 % had completed primary level of education, while 11.0% had completed tertiary education. More than half of the participants (172, 57.5 %) were married 17.7 % were single, 15.1 % were divorced /separated and 9.7 % were widowed. Christians constituted 96% of the respondents while 4 % were Muslims.

Over half of the participants (155, 51.9 %) were employed in the informal sector, 18.7% were in the formal sector while 29.4 % were not employed. 26.4 % ( 79) of the study participants reported to be using alcohol (Table 3).

The median number of years on ARVs was reported at 5(IQR 2-6 years). 59.9% (179) of the participants reported to have been on ARVS for 4 to 7 years, 36.1 %( 108) for below 4 years and only 4 %( 12) reported to have been on ARVs for over 7 years. All the participants reported to have a schedule of two doses per day.

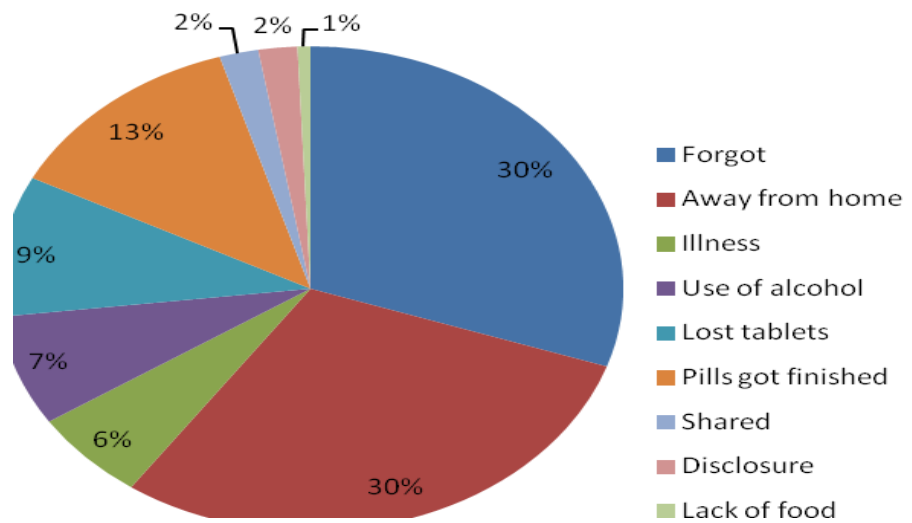
#### 4.1 Level of adherence

**Table 4: Level of adherence**

Measure of Adherence	Self-report on no missed doses		Self-report on Following schedule		Self-report on Following dietary instructions		Optimum adherence	
	Frequency	Percent	Frequency	Percent	Frequency	Percent	Frequency	Percent
Adhered	241	80.6	244	81.6	255	85.3	219	73.2
Did not adhere	58	19.4	55	18.4	44	14.7	80	26.8
Total	N=299	100.0	N=299	100	N=299	100	N=299	100

Three adherence measurements were used in the study. These included self-reported missed doses, self-reported schedule/time adherence and self-reported adherence to dietary instructions. Accordingly, 241 (80.6%) of the study subjects were adherent based on self-report of missed doses (dose adherence) in a four day recall. 244 (81.6%) of the study subjects always followed the schedule/time restrictions (time adherence) agreed upon with their providers and 255 (85.3%) followed dietary instruction always. The information was used to compute the proportion of participants who reported optimum adherence where by one's adherence was considered as optimum if they adhered to all the three adherence measurements. Accordingly, 219 (73.2%) of the participants reported optimum adherence (Table 4).

##### 4.1.1 Reasons for non-adherence to ARVs



**Figure 1: Reasons for Non adherence to HAART**

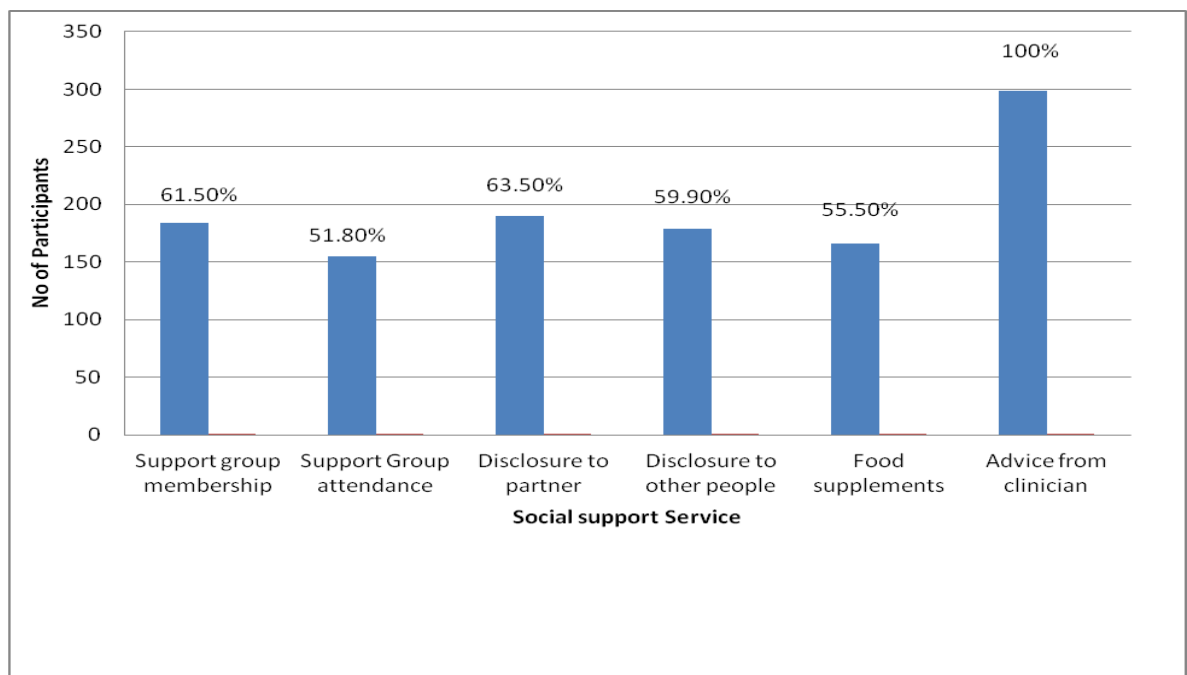
The main reasons given for missing to take drugs were forgetting (30%) and being away from home (30%). The other reasons included use of alcohol, having no food, non-disclosure, loss of tablets, pills getting finished, feeling sick at that time and sharing (Figure 1).

According to the KII, “as much as patients take medication and keep clinic appointment most of them have not incited behavior change, they still smoke drink and even use other drugs hence hindering proper care”.



## 4.2 Uptake of social support services/social integration

N=299



**Figure 2: Uptake of Social Support Services among the Participants**

A total of 184 (61.5%) out of 299 interviewed participants reported to be members of a support group. Only 155 (51.8%) reported to be attending support group meetings often. 190 (63.5%) of them reported to have disclosed their HIV status to their sexual partners, 179 (59.5%) had disclosed their HIV status to other members of the family. 166 (55.5%) of the participants reported to be getting food supplements. Advice from the clinician was reported by all the participants (Figure 2).

Key informants reported that different forms of support are available for the patients and referral depends on the needs of the patients. These included support group therapy, business opportunities, psychosocial counseling, Legal aid, Nutritional support, shelter in case of the abandonment, employment, provision of shelter and handout for fare to the less fortunate patients.

#### 4.2.1 Level of perceived social support

**Table 5: Level of perceived social support**

Member of the community	Frequency N=299	Percentage %
Partner	178	59.5
Child	70	23.4
Friend	123	41.1
Health care provider	293	98.0
Support group members	188	62.9

The participants were asked about how they feel regarding their relationship with people close to them. This information was used to determine their perception about receiving support from these members of the community. 59.5% of the respondents perceived social support from their spouses, 23.4% perceived to be receiving support from their children, 41.1% from their friends, 98% perceived to be receiving support from their health care providers and 62.9% from the support group members. (Table 5). According to Key Informants, “Health care providers play a big role in promoting adherence by providing counseling, patient education, advising patients to come to the clinic with close family members who can be advised on how to assist the patients and referring the patients to social support group to share with other peers on how to cope. The community health workers also play a key role in that they are close to the patient and normally conduct frequent home visits to give reminders on the importance of adherence”.

### 4.3 Demographic factors associated with adherence to ARVs among AMPATH patients

**Table 6: Bivariate analysis to identify the demographic factors associated with adherence to ARVs among AMPATH patients**

VARIABLE (N=299)	Group	Optimum adherence		Crude			P VALUE
		YES	NO	O.R.	95% CI (Crude O.R)		
AGE	18-24	19	17	Reference			
	25-34	<b>108</b>	<b>30</b>	<b>3.221</b>	<b>1.492</b>	<b>6.952</b>	<b>0.003</b>
	35-44	<b>58</b>	<b>20</b>	<b>2.595</b>	<b>1.133</b>	<b>5.942</b>	<b>0.024</b>
	45-54	26	10	2.326	0.873	6.197	0.091
	55 & above	8	3	2.386	0.543	10.476	0.249
GENDER	Male	86	22	Reference			
	Female	133	58	1.705	0.973	2.987	0.062
EDUCATION	Primary	72	33	Reference			
	Secondary	118	43	1.258	0.73	2.158	0.405
	tertiary	<b>29</b>	<b>4</b>	<b>3.323</b>	<b>1.080</b>	<b>10.221</b>	<b>0.036</b>
MARITAL STATUS	Single	39	14	Reference			
	Married	129	43	1.077	0.534	2.172	0.836
	Separated	31	14	0.795	0.330	1.913	0.608
	Widowed	20	9	0.798	0.295	2.160	0.656
RELIGION	Christian	210	77	Reference			
	Muslim	9	3	0.909	0.240	3.446	0.889
No. of children	None	24	10	Reference			
	1 and 2	95	33	1.199	0.519	2.771	0.670
	3 and 4	82	27	1.265	0.537	2.980	0.590
	5 and above	18	10	0.750	0.258	2.183	0.598
INCOME	Formal	43	13	Reference			
	Informal	106	49	0.654	0.323	1.326	0.239
	None	70	18	1.176	0.524	2.634	0.695
Takes alcohol	Yes	60	19	Reference			
	No	159	61	1.212	0.669	2.195	0.527

At bivariate level, age was found to be associated with overall adherence index. Those aged between 25 and 34 years were 3 times more likely to report optimum adherence as compared to those aged below 25 years. (Unadjusted OR=3.221, 95% CI: 1.5 – 6.95, P = 0.003). Those who had tertiary level of education were 3 times more likely

to report optimum adherence as compared to those with primary level of education (Unadjusted OR=3.323, 95% CI: 1.1 – 10.2 , P = 0.036). Females were almost 2 times more likely to report optimum adherence as compared to males but this difference was not statistically significant. ( Unadjusted OR=1.705, 95% CI: 0.973-2.987, P= 0.062). There was no difference in adherence between those who reported to be taking alcohol and those who did not (Unadjusted OR=1.212, 95% CI: 0.669 – 2.195, P = 0.527). There was no association between marital status and adherence and same case applied to religion (table 6). According to in depth interviews, the adherence of a patient depends on how well the patient is versed with the consequences of not taking ARVS as prescribed and also on their self-esteem and support networks that the individual has when they start using the drugs.

#### 4.4 Association between social support and adherence to ARVS among AMPATH patients.

**Table 7: Association between social support and adherence to HAART.**

Independent variable	group	Optimum adherence		Crude O.R.	95% CI (Crude O.R.)	P VALUE	
		YES	NO				
Disclosure To Partner	yes	152	38	<b>2.507</b>	<b>1.484</b>	<b>4.237</b>	<b>0.001</b>
	no	67	42	Reference			
Disclosure To Others	yes	138	41	<b>1.621</b>	<b>0.966</b>	<b>2.718</b>	<b>0.067</b>
	no	81	39	Reference			
Attend Support Group	yes	125	50	<b>2.216</b>	<b>1.310</b>	<b>3.750</b>	<b>0.002</b>
	no	94	30	Reference			
Food Supplement	yes	120	46	1.116	0.666	1.872	0.667
	no	99	34	Reference			
Support Group Membership	yes	148	36	<b>2.347</b>	<b>1.393</b>	<b>3.953</b>	<b>1</b>
	no	71	44	Reference			
Perceived Support Partner	yes	138	40	<b>1.704</b>	<b>1.016</b>	<b>2.857</b>	<b>0.043</b>
	no	81	40	Reference			
Perceived Support Child	yes	61	9	<b>3.046</b>	<b>1.433</b>	<b>6.472</b>	<b>0.004</b>
	no	158	71	Reference			
Perceived Support Friend	yes	90	33	0.994	0.591	1.672	0.981
	no	129	47	Reference			
Perceived Support Doctor	yes	215	78	1.378	0.248	7.674	0.714
	no	4	2	Reference			
Perceived Support Group	yes	139	49	1.099	0.649	1.862	0.729
	no	80	31	Reference			

At bivariate level, those who had disclosed their HIV status to their partners were two and a half times more likely to report optimum adherence as compared to those who had not. (Unadjusted OR=2.507, 95% CI: 1.5 – 4.2, P = 0.001). Those who had disclosed their HIV status to other family members were one and a half times more likely to report optimum adherence as compared to those who had not but this

association was not significant (unadjusted OR=1.621, 95% CI: 0.966 – 2.718, P = 0.067). Participants who reported to be attending support group were 2 times more likely report optimum adherence as compared to those who had not (Unadjusted OR=2.216, 95% CI: 1.310 – 3.75, P = 0.002). Support group membership was also positively associated with good adherence (unadjusted OR=2.347, 95% CI: 1.393 – 3.953, P = <0.0001). Those who perceived to be getting support from their partners were more than one and a half times more likely to report optimum adherence as compared to those who did not (unadjusted OR=1.704, 95% CI: 1.016 – 2.857, P = 0.043). Perceived support from child was also positively associated with optimum adherence (unadjusted OR=3.046, 95% CI: 1.433 – 6.472, P = 0.004). There was no association between other forms of social support and adherence to HAART. (Table 7).

**Table 8: Multivariate logistic regression to determine the association between social support and overall adherence among the study participants**

	B	df	P value	Adjusted O.R.	95% C.I.for Adjusted O.R.	
					Lower	Upper
Age (below 25 years)		4	.050			
Age (25 -34 years)	1.211	1	.005	3.357	1.444	7.808
Age (35-44years)	.984	1	.035	2.676	1.074	6.666
Age (45-54 years)	.474	1	.387	1.607	.549	4.707
Age (55 and above)	.100	1	.906	1.105	.209	5.834
Gender(Females)	1.028	1	.002	2.796	1.454	5.377
Disclosure to Partner(yes)	.887	1	.002	2.427	1.374	4.286
Support Group Membership(yes)	.985	1	.001	2.678	1.507	4.759
Perceived support from child(yes)	1.065	1	.010	2.900	1.288	6.533
Constant	-1.453	1	.002	.234		

At multivariate level, those belonging to a support group were two and a half times more likely to report optimum adherence as compared those who did not belong to a support group (Adjusted OR=2.68, 95% CI: 1.51 – 4.76, P = 0.001). Those who had disclosed their status to their partners were almost two and a half times more likely to report optimum adherence as compared to those who did not (adjusted OR=2.43, 95% CI: 1.37 – 4.29, P = 0.002). Participants who perceived to be getting support from their children were almost 3 times more likely to report optimum adherence compared to those who did not (Adjusted OR=2.90, 95% CI: 1.29 – 6.53, P = 0.01) (Table 8). Age and gender remained as predictors of adherence outcome (table 8). Those aged between 25 and 34 were 3 times more likely to report optimum adherence as compared to those aged below 25 years (adjusted OR=3.36, 95% CI: 1.44 – 7.81, P = 0.005). Females were almost three times more likely to report optimum adherence as compared to males (adjusted OR=2.80, 95% CI: 1.45 – 5.38, P = 0.002) (Table 8). From the KII data, support groups provide a chance for role modeling, Educational sessions, open sharing of experiences by those members who have been on treatment for a long time, Discussing fear of unknown or false information from other quotas, they also challenge and build one another.

Most of the Key informants reported that disclosure to spouses is likely to lead to higher adherence rates because of the ability to take medication and attend clinic without fear. “Quite difficult in some communities but with good counseling right from the testing centre, this becomes less of a burden making it easy to take HAART”, Another respondent said “ once the people you stay with or live with like children or partner knows what you are taking, they are bound to be reminding you to take your medication and they are also bound to be concerned to see that you attend your clinic without fail, It allows one to be willing to have treatment buddy and take

medication as required". Another respondent said that it can affect both positively and negatively. When ones status is known by another member of the family, it may lead to stigmatization hence patients should be prepared to deal with whatever the outcome after the disclosure.



## CHAPTER FIVE:

### Discussion

Successful antiretroviral treatment is dependent on sustaining high rates of adherence. Poor treatment adherence allows HIV to multiply thereby increasing the viral load. The virus also gets a chance to change form and become resistant to the medication. Highly active antiretroviral therapy (HAART) adherence levels of 95% and above optimize outcomes and minimize HIV drug resistance.<sup>(4)</sup> Most of the previous studies in Kenya were using only a single measurement of adherence which is dose adherence<sup>(51)</sup>. In this study, the time restriction (time/schedule adherence) and dietary instructions (food adherence) in addition to self-reported dose adherence measurement were also used.

### 5.0 Level of adherence to HAART

The overall rate of self-reported adherence in this study based on the combined indicator of the three adherence measures of dose, time and dietary restrictions was 73.2%. This is consistent with the prevalence of adherence in Africa which is reported at 77 % according to a Meta review of articles and abstracts from sub-Saharan Africa<sup>(5)</sup>. Other studies conducted in developed countries demonstrated that the rates of adherence by self-report ranged from 40% to 70%<sup>(53, 54)</sup>. According to a prospective study in South-West Ethiopia, the rate of self-reported adherence in the study area based on the combined indicator of the three adherence measures (schedule, instructions and dose) was 75.7%.<sup>(54)</sup> Another study done in South Africa reported that 70.8% of the participants were adherent but pointed out that these good rates may decline the longer the participants are on treatment<sup>(55)</sup>. A Botswana study showed that 81.3% of patients were adherent based on a four day recall period<sup>(56)</sup>. The level of

adherence in this study is from a sample of patients with varied time on ART with a median of 5 years.

The rate of adherence to HAART in resource limited countries is higher than in developed world. Some resource-rich settings have documented less than 50% of patients taking all their antiretroviral medications on time and according to dietary instructions <sup>(4)</sup> which are lower than the findings of this study confirming that patients in developing countries can achieve good adherence despite limited resources. The strict adherence counselling given at the clinic before commencing the treatment could be a good explanation for the high prevalence of adherence reported in this study and other resource limited settings.

### **5.1 Reasons for non-adherence to HAART**

This study found that the main reasons given for not adhering to taking medication were forgetting, being away from home and pills getting finished due to missed appointments. In a study done in South West Ethiopia, the principal reasons reported for missing doses were mainly forgetting, falling sick and running out of medication <sup>(54)</sup>. The other reasons included losing tablets, lack of food to take with the medication, illness and sharing. Other barriers to treatment included running out of medications because of sharing, lack of disclosure and use of alcohol. These results are also consistent with a study done in Kenya which reported the main reasons for missing tablet as being away from home, forgetting or being too busy.<sup>(58)</sup> Forgetfulness as a barrier suggests that patients could be very busy with other duties at home and work place until they forget to take their drugs. Reminder tools could come in handy in helping patients to remember to take their drugs as prescribed. Other reasons reported implicate that this should be given due emphasis at the clinic,

dispensing point and also during ongoing adherence counselling. Other interventions aimed at maintaining adherence, and thereby optimizing the benefit of effective therapies should be sought in detail by health care workers.

## **5.2 Determinants of adherence to HAART**

Age and gender were found to have an effect on adherence. Those who were aged between 25 and 34 years were almost four times more likely to report optimum adherence compared to those aged below 25 years of age. Those between the ages of 35-44 years were 3 times more likely to report optimum adherence compared to those below 25 years. This was consistent with findings of other studies done in Nigeria, South Africa and USA <sup>(59, 60, 61)</sup>. The reasons for this could be that taking medication requires less alteration in lifestyle for people who are older. Older individuals are more likely to have prior experience taking medication for other age-related illnesses and therefore may already have become more accustomed to such a routine. Secondly, it may be that the lifestyle alterations necessary for successful adherence are less burdensome for older individuals, who may more easily be able to accommodate pill-taking into their daily lives. Older age may also be associated with increased recognition of mortality and therefore greater motivation to follow illness prevention strategies and treatment recommendations set forth by health care providers. Alternatively, increased medication adherence among older adults may be explained, in part, by a survivor effect in that individual who maintain greater compliance with treatment recommendations may actually outlive those who are less adherent.

The young ones may also not have been well informed and experienced about the effects of not taking the medication as required hence this kind of trend. At bivariate level, high level of education was positively associated with adhere optimum

adherence. Other studies have shown that higher level of education is associated with optimum adherence<sup>(55, 62)</sup>. High level of knowledge as a result of higher education means that they are well aware of reasons for taking drugs as prescribed hence enabling them to make more informed decision about the importance of high level of adherence.

From the findings, females were more likely to report optimum adherence as compared to males. A study done in Kenya found that there was no difference between males and females with respect to following time adherence.<sup>(58)</sup> This difference could be due to the different methods used in measuring adherence between the two studies.

### **5.3 Uptake of social support services**

More than half of the study participants belonged to a support group. A similar finding was reported in a study done in Kenya which reported that 61% of the participants from urban areas were in support groups<sup>(63)</sup>. This could be due to the fact that all the patients are normally advised to join support groups by their healthcare providers hence the high uptake of this particular support service. Below 50% reported to be attending support group meetings. According to a study done in South Africa, only 41.9% reported to have ever attended a support group meeting<sup>(64)</sup>. Some of the reasons why people do not attend support group meetings are fear of disclosure of HIV status, perceptions that attendance means inability to cope with one's status and perception of support groups as depressing. All the participants reported to be receiving advice from their health care provider. It is a requirement that counselling is done before the ARVs are dispensed to the participants.

Disclosure to Sexual partners in this study was higher compared to a study done in Ethiopia which reported that 50.7% had disclosed to their spouses. This could be attributed to the fact that counselling services that are provided in the AMPATH clinics emphasize on the importance of having pill buddies hence the importance of disclosure. Disclosure to other people was reported by 59.9%. In a study done in South Africa, 91% had disclosed to other people while for a study done in Ethiopia, the prevalence of disclosure to others was 51.9%.<sup>(57)</sup> This prevalence of disclosure is relatively high and it could be due to counselling done at the clinics which encourage disclosure to enhance adherence.

#### **5.4 Association between social support and adherence to ARVs**

In this study, belonging to a support group was positively associated with optimum adherence. According to a study done in Mozambique between 2008 and 2010, support groups led to increase in adherence to HAART<sup>(65)</sup>. A qualitative study done in Columbia found that participation in support groups was associated with higher adherence to HAART.<sup>(66)</sup> Another study found that using support networks as reminder tools was positively associated with adherence.<sup>(67)</sup> Being a member of a support group encourages the patient that they are not alone; there are other people who are in a situation like theirs and this is expected to be a motivation to take their medication as required. There was also the aspect of perceived support just because one is a member of a support group.

From this study all the participants reported to be receiving support from their physician/health care provider. Perceived support from health care providers had no effect on adherence in this study. From other studies, the quality of the patient-physician relationship has been reported to play an important role in promoting

adherence. Dedicating time towards effective communication regarding adherence may strengthen a provider-patient relationship that in turn promotes adherence through trust. <sup>(68)</sup> Even though counseling by clinicians was not statistically significantly associated with adherence, the high rates of 73.2% observed in this study indicate the seriousness with which the Health care providers have taken their work of supporting their patients at the AMPATH Clinic, MTRH.

Disclosure of HIV status to sexual partners was positively associated with optimum adherence. This was consistent with studies done in Botswana, Ethiopia and Nepal which found that those who had disclosed their status got family support and were more likely to adhere than those who had not disclosed their status and did not get the family support <sup>(56, 57, 69)</sup>. This could be attributed to the fact that the sexual partners encourage and help to remind the patients to take the treatment. Similarly, it has been reported in another study that living in a couple is a constant predictor of adherence <sup>(53)</sup>. Disclosure to one's sexual partner has however been recognized as a double edged sword since it could lead to stigmatization <sup>(65)</sup> but it has the potential to yield much needed social support <sup>(67)</sup>. It has however been reported that adherence is associated more with functional support than living arrangement/relationship status <sup>(4)</sup>. Practical support also has a significantly greater influence on adherence than emotional support <sup>(70)</sup>. This highlights that social support as a result of disclosure assist in reminding patients to take the drugs as prescribed.

There was a significant association between perceived support from children and reporting optimum adherence. This was possibly due to the fact that children are known to provide emotional support and also act as treatment buddies making it possible to overcome issue of forgetting to take medication. Children do make good

treatment buddies because they are good at remembering when it is time to take the medication. According to a study done in South Africa, support of a treatment buddy resulted in better adherence outcomes compared to those who did not report this kind of support <sup>(71)</sup>. According to a study conducted in South Africa, treatment supporters namely clinic buddies are a valuable aid in promoting adherence. In this study done to assess the impact of a community-based adherence support service established that (89%) of patients with a community-based adherence supporter (also known as a patient advocate, attained a treatment pickup rate of over 95% (p=0.021). Patients at health facilities with Patient advocate services maintained lower viral load for a longer period as opposed to patients at health facilities without patient advocate services (p=0.001). Also patients at health facilities with patient advocate services remained in care for longer periods (p=0.001). The study concluded that integrated community-based adherence support is crucial in ensuring that patients remain in care and regularly pickup their treatment from ART <sup>(72)</sup>.

### **5.5 Study limitations:**

The findings of this study should be interpreted with some limitations, because it was conducted at a single site. The findings may not be generalized to non-similar clinical settings. Recall bias and social desirability bias are also the possible bias which may have been encountered in this study. There is no gold standard for measuring adherence and our measurement of adherence is only based on patients' declarations of missed doses, scheduling instructions and dietary requirements. Despite the above limitations, the study addressed an important issue in developing countries, and inclusion of several variables that predict adherence and to fully characterize the study population, other dimensions of adherence measurement were included for successful

treatment with ART (adhering to scheduling and to dietary instructions) and the sample size was reasonably large.

### **5.6 Conclusion**

The adherence rate found in this study is similar to other resource limited settings. The results also suggest that female gender, age of 25-34, belonging to a support group, disclosure of HIV status to partner and perceived support from children were positively associated with reporting optimum adherence.

### **5.7 Recommendations**

The study targeted the aspect of adherence during a time when its importance could not be ignored due to changes in trends and patterns of disease moving from acute to chronic conditions. Because of this fact, AMPATH should focus more on male and young patients with adherence counseling messages to enhance adherence rates. AMPATH should also encourage patients to join support group sessions for psychosocial support therapy to promote adherence to ART. Client counseling on adherence by AMPATH service providers should be maintained to facilitate good levels of adherence. Health care providers should also encourage patients to disclose their HIV status to their spouses to enhance support from these members of the family as this has been found to improve adherence even from other studies.

There is need for more study on the mediators between social support and adherence to ARVs including self-efficacy, to be able to understand the association even better.



## REFERENCES

1. UNAIDS. Global report. (2012). UNAIDS report on the global AIDS epidemic 2012. Geneva Switzerland: WHO Library.
2. NACC, NASCOP (2011). Kenya AIDS Epidemic Update. Nairobi, Kenya, 2012.
3. World Health Organization: (2006). Antiretroviral therapy of HIV infection in infants and children in resource-limited settings: Towards universal access. Recommendations for a public health approach.
4. Carter M (2005). Adherence. Information series for HIV Positive people. NAM, 2005 Available at: <http://www.aidmap.com>
5. Mills, E, Nachega J, Buchan I, Orbinski J, Attaran A, Singh S, Rachlis B, Wu P, Cooper C, Thabane L, Wilson K, Guyatt G, Bangsberg D: (2006). Adherence to antiretroviral therapy in sub-Saharan Africa and North America: a meta-analysis. JAMA 296(6):679-90.
6. Gill, C.J, Hamer D.H, Simon J.L, Thea DM, Sabin L.L. (2005). No room for complacency about adherence to antiretroviral therapy in sub-Saharan Africa. AIDS, 19(12):1243-1249.
7. Kleeberger, C.A, Phair J.P, Strathdee S.A, Detels R, Kingsley L, Jacobson L.P. Changes in adherence to highly active antiretroviral therapy medications in the Multicenter AIDS Cohort Study. Journal Acquir Immune DeficSyndr. 2001 Jan 1; 26(1):82-92.
8. Pallela, F.J, Delaney K.M, Moorman A.C, et al. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. New England Journal of Medicine, 338 (13):853-860.
9. AIDS in Kenya, Trends, Interventions and Impact, 7<sup>th</sup> edition 2005
10. Chesney MA (2000). Factors affecting adherence to antiretroviral therapy Clinical Infectious Diseases, 30(Suppl 2):S1716 2000.
11. DiMatteo, M.R, DiNicola D.D, eds. (1982). Achieving Patient Compliance. New York: Pergamon Press; 1-28.
12. Bond, W, Hussar D.A. (1991). Detection methods and strategies for improving medication compliance. Am J Public Health. 81:1978-1988.
13. Bangsberg, D.R, Hecht F.M, Charlebois EC, et al. Spontaneous adherence audits predict viral suppression in the REACH cohort. In: Program and abstracts of the 6th Conference on Retroviruses and Opportunistic Infections; January 31-February 4, 1999; Chicago. Abstract 93.

14. Golin, C, Liu H, Hays R, et al. (1999). Self-reported adherence to protease inhibitors substantially overestimates an objective measure. In: Program and abstracts of the 6th Conference on Retroviruses and Opportunistic Infections; January 31-February 4, Chicago. Abstract 95.
15. Cramer, J.A, Mattson R.H, Prevey M.L, et al. (1989). How often is medication taken as prescribed? A novel assessment technique. *JAMA*. 261:3273-3277.
16. Greene D, Goehring C, Saaidia A, et al. Macrocytosis in patients with HIV infection: after zidovudine. In: Program and abstracts of the 12th World AIDS Conference; June 28-July 3, 1998; Geneva. Abstract 32156.
17. Richardson, D, Liou SH, Kahn JO. (1993). Uric acid and didanosine compliance in AIDS clinical trials: an analysis of AIDS Clinical Trials Group protocols 116A and 116B/117. *J Acquir Immune Defic Syndr*. 6:1212-1223.
18. Roca, B, Peris M.L, Colom I. (September 26-29, 1999). Relationship between increased bilirubin levels and adherence to an indinavir-containing HAART regimen. In: Program and abstracts of the 39th Interscience Conference on Antimicrobial Agents and Chemotherapy; San Francisco. Abstract 599.
19. Kastrissios, H, Suarez J.R, Hammer S, et al. (1998). The extent of non-adherence in a large AIDS clinical trial using plasma dideoxynucleoside concentrations as a marker. *AIDS*. 12:2305-2311.
20. Cramer, J.A. (1991). Overview of methods to measure and enhance patient compliance. In: *Patient Compliance in Medical Practice and Clinical Trials*. New York: Raven Press: 3-10.
21. WHO (2003). *Adherence to Long-term Therapies: Evidence for Action*. Washington, D.C., World Health Organization (WHO) 2003.
22. Orrell, C, D. R. Bangsberga, Motasim B. and RobinW, (2003). Adherence is not a barrier to successful antiretroviral therapy in South Africa. *AIDS* 2003, 17:1369–1375
23. Rao, D., Kekwaletswe T. C, Hosek S., Martinez J., & F. Rodriguez (2007). “Stigma and social barriers to medication adherence with urban youth living with HIV” *AIDS Care*:19(1) 28 – 33.
24. Weiser, S. Wolfe, W. & D. Bangsberg. (2003). “Barriers to Antiretroviral Adherence to patients living with HIV infection and AIDS in Botswana” *J Acquir Immune Defic Syndr* 34(3):281-288.
25. Hardon, A., et al. (2006). “From access to adherence: The challenges of antiretroviral treatment. Studies from Botswana, Tanzania and Uganda”. Geneva, Switzerland: World Health Organization.

26. Skhosana, N.L Struthers, H, Grauy, E.G, and McIntyre. (2006). "HIV disclosure and other factors that impact on adherence to antiretroviral therapy: the case of Soweto, South Africa" *African Journal of AIDS Research* 5(1):17-26
27. Marelich, W. D, K. Johnston Roberts; Murphy, D.A., and T. Callari. (2002). "HIV/AIDS patient involvement in antiretroviral treatment decisions. *AIDS Care* 14 (1): 17-26.
28. Forsyth, D. R. (1999). *Group Dynamics*. Belmont, CA: Brooks/Cole.
29. Barerra, M., Jr. (1986). Distinctions between social support concepts, measures, and models. *American Journal of Community Psychology*, 14, 413-445.
30. Milan J, Richardson JL, McCutchan A, et al. (2005). Effect of brief antiretroviral adherence intervention delivered by HIV care providers. *JAIDS*; 40(3):356-363.
31. Laireiter, A., and Baumann, U. (1992). Network structures and support functions: Theoretical and empirical analyses, the meaning and measurement of social support (pp. 33-55). Washington, DC: Hemisphere.
32. Rotheram-Borus, M. J., Lee, M. B., Gwadz, M., & Draimin, B. (2001). An intervention for parents with AIDS and their adolescent children. *American Journal of Public Health*, 91, 1294-1302.
33. Song, J., Lee, M., Rotheram-Borus, M. J., & Svendeman, D. (2006). Predictors of intervention adherence among young people living with HIV. *American Journal of Health Behavior*, 30, 136–146.
34. Fekete, E.M., Antoni, M.H., Lopez, C.R., Duran, R.E., Penedo, F.J., Bandiera, F.C., Schneiderman, N. (2009). Men's serostatus disclosure to parents: Associations among social support, ethnicity, and disease status in men living with HIV. *Brain, Behavior, and Immunity*, 23, 693–699.
35. DiIorio, C., McCarty, F., DePadilla, L., Resnicow, K., Holstad, M.M., Yeager, K., Lundber, B. (2009). Adherence to antiretroviral medication regimens: A test of a psychosocial model. *AIDS Behavior*, 13, 10–22.
36. Song, Y.S., & Ingram, K.M. (2002). Unsupportive social interactions, availability of social support, and coping: Their relationship to mood disturbance among African Americans living with HIV. *Journal of Social and Personal Relationships*, 19, 67–86.
37. Anita, P.H, Dorothy A. A, Christopher C, Cosmas E, et al. (2006). On hunger, transport costs and waiting time: a synthesis of challenges to ARV adherence in three African countries.
38. Simoni J.M, Frick P, Pantalone D, et al. (2003). Antiretroviral adherence interventions: a review of current literature and ongoing studies. *Topics HIV Med.* 11:185-98.

39. Kent, D.M et al. (2003). Suitable monitoring approaches to antiretroviral therapy in resource poor settings: setting the research agenda. *Clinical Infectious Diseases*, 37(Suppl 1):S13-24.
40. Farmer, P., F. Léandre, J. Mukherjee, et al. (2001). Community based approaches to HIV treatment in resource poor settings. *Lancet*, 358:404-409.
41. Remien, RH, Stirrat MJ, Dolezal C, Couple-focused support to improve HIV medication adherence: a randomized controlled trial. *AIDS* 2005; 19(8):807-814.
42. Hsu, J. Adherence. Johns Hopkins Point of Care Information Technology. 2005, January 24. Available at: [www.hopkins-hivguide.org](http://www.hopkins-hivguide.org).
43. Wills, T. A., & Shinar, O. (2000). Measuring perceived and received social support. In S. Cohen, L. G. Underwood, & B. H. Gottlieb (Eds.), *Social support measurement and intervention: A guide for health and social scientists* (pp. 86–135). New York: Oxford University Press.
44. Lakey, B., & Cohen, S. (2000). Social support theory and selecting measures of social support. In S.Cohen, L. U. Gordon & B. H. Gottlieb (Eds.) *Social support measurement and interventions: A guide for health and social scientists*. New York: Oxford.
45. Barrera, M., Sandler, I. N., & Ramsey, T. B. (1981). Preliminary development of a scale of social support: Studies on college students. *American Journal of Community Psychology*, 9, 435-447.
46. Sidle J., Kimaiyo S.I. Patterns of antiretroviral adherence among Kenyan patients and factors related to non-adherence during the first year of treatment presented at the 4th IAS Conference on Pathogenesis, Treatment and Prevention (IAS 2007).
47. Chesney MA, Ickovics JR, Chambers DB, Gifford AL, Neidig J, Zwickl B, Wu AW: (2000). Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: the AACTG adherence instruments. Patient Care Committee & Adherence Working Group of the Outcomes Committee of the Adult AIDS Clinical Trials Group (AACTG). *AIDS Care* 12(3):255-266.
48. Maneesriwongul, W.L, Tulathong S, Fennie K.P, Williams A.B: (2006). Adherence to antiretroviral medication among HIV-positive patients in Thailand. *J Acquir Immune Defic Syndr* 43(1):S119-S122.
49. Sarna A, Luchters S, Geibel P, Munyao S, Kaai K, Shikely K: (2005). Promoting adherence to antiretroviral therapy through a directly administered antiretroviral therapy (DAART) strategy in Mombasa, Kenya. Nairobi: Population Council.
50. Schulz U, Schwarzer R. (2003). Social support in coping with illness: The Berlin Social Support Scales (BSSS)]. *Diagnostica*. 49: 73-82.
51. Fisher, Jeffrey D., William A. Fisher, K. Rivet Amico, and Jennifer J. Harman.

- "An Information-motivation-behavioral Skills Model of Adherence to Antiretroviral Therapy." *Health Psychology* 25.4 (2006): 462-73.
52. Chesney, M.A: (2000). Factors affecting adherence to antiretroviral therapy. *Clin Infect Dis* 30(suppl 2):S171-S176.
  53. Nieuwkerk, P.T, Sprangers M.A, Burger D.M, et al.: Limited patient adherence to highly active antiretroviral therapy for HIV-1 infection in an observational cohort study. *Arch Intern Med* 2001, 161:1962-1968.
  54. Amberbir, A, Woldemichael K, Getachew S, et al.: (2008). Predictors of adherence to antiretroviral therapy among HIV-infected persons: a prospective study in Southwest Ethiopia. *BMC Public Health*
  55. Karl, Peltzer, Natalie Friend-du Preez, Shandir Ramlagan and Jane Anderson. (2010). Antiretroviral treatment adherence among HIV patients in KwaZulu-Natal, South Africa. *BMC Public Health* 10:111 doi:10.1186/1471-2458-10-111.
  56. Do, N., K. Phiri, H. Bussmann, T. Gaolathe, R. Marlink and W. Wester. (2010). "Psychosocial Factors affecting Medication Adherence among HIV-1 Infected Adults Receiving Combination Antiretroviral Therapy (cART) in Botswana." *AIDS Research and Human Retroviruses* 26 (6): 685-691.
  57. Ayele Tiyou, Tefera Belachew, Fisehaye Alemseged and Sibhatu Biadgilign. (2010). Predictors of adherence to antiretroviral therapy among people living with HIV/AIDS in resource-limited setting of southwest Ethiopia. *AIDS Research and Therapy*, 7:39 doi:10.1186/1742-6405-7-39.
  58. Talam, N.C. Gatongi P., Rotich J., Kimaiyo S. (August 2008). Factors affecting antiretroviral drug adherence among hiv/aids adult patients attending HIV/AIDS clinic at Moi teaching and referral hospital, eldoret, kenya. *East african journal of public health* volume 5 2 pg74.
  59. Iliyasu, Z, Kabir M, Abubakar I.S, Babashani M, Zubair Z.A. (2005). Compliance to antiretroviral therapy among AIDS patients in AminuKano Teaching Hospital, Kano, Nigeria. *Niger. J. Med.*, 14(3): 290-294.
  60. Orrell, C, D. R. Bangsberga, Motasim B. & Robin W, (2003). Adherence is not a barrier to successful antiretroviral therapy in South Africa. *AIDS* 2003, 17:1369–1375.
  61. Terry, R. Barclay, Charles H. Hinkin, Steven A. Castellon, Karen I. Mason, Matthew J. Reinhard, Sarah D. Marion, Andrew J. Levine, and Ramani S. Durvasula. (2007 January). Age-Associated Predictors of Medication Adherence in HIV-Positive Adults: Health Beliefs, Self-Efficacy, and Neurocognitive Status-*Health Psychol.* 26(1): 40–49.
  62. Birbeck, G.L, Chomba E, Kvalsund M, Bradbury R, Mang'ombe C, (2009). Antiretroviral adherence in Rural Zambia; the first year of treatment availability. *Am J Trop Med.*;80:669–74.

63. Kako, P.M., Stevens,P.E. Mkanda, L. Valhmu W, Kibicho J. (2012). Identifying barriers to support group attendance: insights from women living with HIV in Kenya WEPE386 - Poster Exhibition I.A.S.
64. Sphiwe Madiba, Olga Kekana. (2013). “Factors Associated with Attendance and Non-Attendance of Support Groups among HIV Positive Adults Attending an Antiretroviral Community Clinic at Ekurhuleni District, South Africa” *World Journal of AIDS*, 3, 111-118.
65. Decroo, T., B. Telfer, M. Biot, J. Maikere, S. Dezembro, L. Cumba, C. das Dores, K. Chu and N. Ford. (2011). “Distribution of Antiretroviral Treatment through Self-forming Groups of Patients in Tete Province, Mozambique.” *Journal of Acquired Immune Deificiency Syndromes* 56 (2): e39e44.
66. Arrivillaga, M., M. Ross, B. Useche, A. Springer and D. Correa. (2011). “Applying an Expanded Social Determinant Approach to the Concept of Adherence to Treatment: The Case of Colombian Women Living with HIV/AIDS.” *Women’s Health Issues* 21 (2): 177-183
67. Ramadhani, H.O, Thielman N.M, Landman K.Z, Ndosi E.M, Gao F. (2007). Predictors of incomplete adherence, virologic failure, and antiviral drug resistance among HIV-infected adults receiving antiretroviral therapy in Tanzania. *Clin Infect Dis.*; 45:1492–8.
68. Watt, M.H, Maman S, Earp JA, Eng E, Setel P.W, et al. (2009). “It's all the time in my mind”: facilitators of adherence to antiretroviral therapy in a Tanzanian setting. *Soc Sci Med* 68: 1793–1800
69. Wasti, S.P, Simkhada P, Randall J, Freeman J.V, van Teijlingen E (2012). Factors Influencing Adherence to Antiretroviral Treatment in Nepal: A Mixed-Methods Study. *PLoS ONE* 7(5): e35547. doi:10.1371
70. Strawford, A, Hellerstein M (1998). The etiology of wasting in the human immunodeficiency virus and acquired immunodeficiency syndrome. *Seminars in Oncology*, 25 April, (Suppl 6):768135.
71. Wouters, E., W. van Damme, F. van Loon, D. van Rensburg and H. Meulemans. (2009). “Public-sector ART in the Free State Province, South Africa: Community Support as an Important Determinant of Outcome.” *Social Science & Medicine* 69: 1177-1185.
72. Igumbor, J.O., et al., (2011 Feb). An evaluation of the impact of a community-based adherence support programme on ART outcomes in selected government HIV treatment sites in South Africa. *AIDS Care*. 23(2): p. 231-6.

## APPENDICES:

### Appendix I: Questionnaire: Interview with Patients

Date of interview:      Questionnaire No:      interviewer's initials.....Module

--	--	--	--	--	--

--	--

--	--

This is a questionnaire for the effects of social support on adherence to ART among patients attending AMPATH clinic, MTRH, being done by a researcher from Moi University School of Public Health. Findings from this study shall be analyzed and compiled into a thesis for presentation and defense for the degree of Master in Public Health of Moi University. Questions regarding to your demographic information adherence to ART and social support will be asked from this questionnaire. Once again we want to remind you that some of the questions in this interview may be difficult answer or to remember. Try to give your best answers and be as honest as possible.

### Instructions to Respondents

#### **SECTION 1: DEMOGRAPHIC DATA**

1. When were you born? Dd \_\_\_mm\_\_\_yy\_\_\_ or What is your age (in years) 

--	--
2. Sex                    1) male            2) female
3. Highest level of education level attained  
1) None                    2) primary                    3) secondary                    4) Tertiary
4. Marital status? 1) Single            2) Married            3) Divorced            4) Separated  
5) Widowed
5. What is your Religious Affiliation?  
1) Christian                    2) Muslim                    3) traditional                    4) none  
5) Other (*specify* \_\_\_\_\_)
6. How many living children do you have? /\_\_\_/ /\_\_\_/
7. What is your **MAIN** Source of income?  
1) Formal employment 2) Business 3) Remittances from kin 4) Farming  
5) Others Specify \_\_\_\_\_
8. What is **YOUR** monthly income (*average in the past 3 months*) Ksh \_\_\_\_\_
9. Do you take Alcohol?            1)Yes            2)No

#### **SECTION 2: Medication, Health and Adherence**

10. Number of daily doses .....
11. Treatment starting date dd \_\_\_mm\_\_\_yy\_\_\_
12. How would you rate your health since you started using ARVS?
  - 1) Very poor
  - 2) Poor
  - 3) Average
  - 4) Good
  - 5) Very good

13. When was your last CD4 count done by the doctor? DD \_\_\_\_ MM \_\_\_\_ YY \_\_\_\_  
 14. What was your CD4 count then?

15. During the last 4 days, how many doses did you miss?

Drug	Number of doses per day	Doses missed yesterday	Doses missed 2 days ago	Doses missed the 3 days ago	Doses missed 4 days ago

N/B: if you took a portion of a dose, report it as a missed dose.

16. Do your medication have any special instruction e.g. after meals, before meals, with plenty of fluids? 1) Yes 2) No
17. If yes, how many days did you follow the instructions over the last 4 days?  
 1) Never  
 2) Some of the time  
 3) About half of the time  
 4) Most of the time  
 5) All of the time
18. Most of the medications need to be taken on a schedule e.g. twice a day, thrice a day, every 8 hours. How closely did you follow the schedule?  
 1) Never  
 2) Some of the time  
 3) About half of the time  
 4) Most of the time  
 5) All of the time
19. Some people forget to take their pills over the weekend. Did you miss taking your pills over last weekend? 1) Yes 2) No
20. When was the last time you missed taking any of your medications?  
 1) Within the past week  
 2) 1-2 weeks ago  
 3) 2-4 weeks ago  
 4) 1-3 months ago  
 5) More than 3 months ago  
 6) Never skipped medication

### **SECTION 3: Reason for Missing to Take Medication**

21. During the last one month, what has caused you not to take your pills?

- 1) N/A (not missed any dose) 6) lost tablets  
 2) Forgot 7) side effects  
 3) Away from home 8) pills got finished  
 4) Illness 9) shared tablets with someone else  
 5) Use of alcohol 10) others (specify) \_\_\_\_\_



**Section 4: Pill Reminders**

- 22 What has been helping you to remember to take your pills?
- |               |                                      |
|---------------|--------------------------------------|
| 1) Nothing    | 6) other members of your family      |
| 2) Pill diary | 7) your partner                      |
| 3) Pill chart | 8) associates it with daily activity |
| 4) Pill box   | 9) others (specify) _____            |
| 5) Alarm      |                                      |

**Section 5: Disclosure**

- 23 Have you disclosed your HIV status to your sexual partner? 1) Yes 2) No (go to 25)
- 24 Has this affected the way you take your ARVS? 1) Yes 2) No If yes how? \_\_\_\_\_
- 25 Have you disclosed your HIV status to any other person? 1) Yes 2) No If yes who? \_\_\_\_\_
- 26 Has this affected the way you take your ARVS? 1) Yes 2) No If yes how? \_\_\_\_\_

**SECTION 6: Support Group Attendance**

- 27 Do you belong to a support group? 1) Yes 2) No (go to 28)
- 28 If yes, how often do you attend the support group meetings?
- always
  - most of the times
  - some of the times
  - just a few of the times
  - Do not attend
- 29 Has this affected the way you take your ARVS? 1) Yes 2) No (go to 29)  
If yes how? \_\_\_\_\_

**Section 7: Food Supplements**

- 30 Are you normally given any food supplements or clothing from any source e.g. AMPATH? 1) Yes 2) No
- 31 If yes, how often?
- Once a week or more
  - twice a month
  - Once a month
  - rarely
  - never
32. Has this affected the way you take your medicine? 1) Yes 2) No If yes how? \_\_\_\_\_

**Section 8: Health Care Provider**

33. How does your doctor/nurse react when you have not taken your pills as required? \_\_\_\_\_
34. Does this make you not to want to miss your pills? 1) Yes 2) No

35. Do you sometimes tell the doctor that you have taken your pills when you have not? 1) Yes    2) No
36. How have your doctor/ nurse affected the way you take your ARVS?

37. Think about the person who is closest to you, such as your spouse, partner, child, friend and respond to the following statements (The interviewer should mark the responses for each of the persons listed below)

	Sexual partner				child			
	strongly disagree	somewh at disagree	somewh at agree	strongly agree	strongly disagree	some what disagr ee	somewhat agree	strongly agree
This person truly like me.								
Whenever I am not feeling well, this person shows me that they are fond of me								
Whenever I am sad, this person cheers me up.								
This person is always there for me when I need comforting								
I know this is a person upon whom I can always rely on.								
When I am worried, this person helps me.								
This person offers me help when I need it.								
When everything becomes too much for me to handle, this person is there to help me.								
	Friend				Doctor			
	strongly disagree	somewh at disagree	somewh at agree	strongly agree	strongly disagree	some what disagr ee	somewhat agree	strongly agree
This person truly like me.								
Whenever I am not feeling well, this person shows me that they are fond of me								
Whenever I am sad, this person cheers me up.								
This person is always there for me when I need comforting								
I know this is a person upon whom I can always rely.								
When I am worried, this person helps me.								
This person offers me help when I need it.								
When everything becomes too much for me to handle, this person is there to help me.								
	Support group members				<b>Key score</b> Strongly disagree        1 Somewhat disagree      2 Somewhat agree          3 Strongly agree            4			
	strongly disagree	somewh at disagree	somewh at agree	strongly agree				
This person truly like me.								
Whenever I am not feeling well, this person shows me that they are fond of me								
Whenever I am sad, this person cheers me up.								
This person is always there for me when I need comforting								
I know this is a person upon whom I can always rely.								
When I am worried, this person helps me.								
This person offers me help when I need it.								
When everything becomes too much for me to handle, this person is there to help me.								

**Appendix II: Questions for Key Informant Interviews**

1. What is adherence?
2. Why is it important to adhere to ART regimen?
3. How would you rate the adherence of AMPATH Patients to ARVS
4. What types of social support are offered to the AMPATH patients?
5. How do you think these types of social support affect adherence to ARVS among AMPATH patients?
6. How do the health care providers deal with clients who have not adhered to their regimen?
7. How are clients motivated to take their medication as required?
8. How would you help a patient to adhere to their treatment?
9. How do support groups influence its members' adherence to ART?
10. How does disclosure affect adherence to ART among AMPATH clients?
11. How can spouses help their partners to take their pills?
12. How does provision of food supplements affect adherence to ART among AMPATH patients?

### Appendix III: Consent Form

#### **EFFECTS OF SOCIAL SUPPORT ON ADHERENCE TO ART AMONG PATIENTS ATTENDING AMPATH CLINIC AT MTRH-ELDOROT**

You are invited to participate in a research study on Effects of Social Support on Adherence to ART among Patients Attending AMPATH Clinic at MTRH-Eldoret. The Principal investigator of this study is a Masters student at the School of Public Health of Moi University

**Purpose of the Study:** the purpose of this study is to find out the effects of social support on adherence to ARVs among patients attending AMPATH clinic at MTRH. This study will also find out the number of clients Adhering to ARVS as required and whether the support they get from other people help them in taking drugs as required. This study is also being done for academic purposes and information gathered from this study shall be compiled into a thesis for presentation and defense for the degree of Master in Public Health of Moi University.

**Duration of study:** The whole study shall take 9 months to finish. Your participation in the study however takes the time you are interviewed with the help of a questionnaire (about 30 minutes) or the time you take to participate in a Key Informant Interview (between 45 minutes and 1 hours).

**Number of people taking part in the Study:** If you agree to participate in this study, you will be one among 272 people participating in this study.

**Procedures of the Study:** If you agree to participate in this study, you may respond to a questionnaire or participate in a Key Informant Interview. You will be required to respond to questions raised from a questionnaire or interview guide. Some of the questions may be sensitive. The questions touch different areas that regard adherence and social support. You are free not to answer any question which you are uncomfortable with.

**Voluntary nature of participation in the study:** Participation in this study is voluntary. If you decline to participate, you shall not be discriminated against in any way and your decision shall be respected. You will still be free to continue care at AMPATH. You can leave the study at any time. Leaving the study does not result to any penalty.

**Costs:** There are no added costs to taking part in this study.

**Confidentiality of information:** Information given shall be treated confidentially and will only be used for the purposes of this study. Names of the participants will not in any way be produced in analyzed information, and raw data will be confidentially kept under key and lock, and will only be accessible to study staff. Study staff will be trained on protection of human subjects.

**Feedback on findings:** Findings of this research shall be contained in a thesis submitted to the School of Public Health, Moi University for the award of a degree of Masters in Public Health. Feedback on findings shall also be communicated through a workshop.

**Risks of participating in the study:** Answering questions in this study may make you feel uncomfortable. However, you may choose not to answer a question if it makes you uncomfortable, and you may decide to opt out of the study at any time.

**Benefits associated with participating in this study:** There will be no direct monetary benefits to the individual study participants. However, information generated from this study will be useful in modifying social support policies to promote adherence to ART.

**Alternatives of taking part in the study:** Instead of taking part in the study, you have the option to choose not to participate. If you choose not to participate, you will just continue with your care at AMPATH just as you normally.

**Study Contacts:** More information about this research study, you can contact Kaguiriri, C. Eunice, the Investigator in this research study on 0721788680, or by post through Moi University School of Public Health, P.O Box 4606 Eldoret, Kenya.

**Participants consent:** I have read the foregoing information or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. By signing below, I consent to participate in the study described above, with knowledge that I can withdraw from the study at any time.

Participants Name.....Participants Signature/Thumb print.....  
 Name and signature of study staff consenting .....Date.....  
 Name and signature of witness (*if participant is illiterate*) .....

***NB:** If participant does not know how to read and write, a witness shall be required. In such a case the participant shall put the left thumb print in the space provided for him, whilst the witness shall be required to sign in the area provided for the witness.*

### Appendix IV: Google Map of AMPATH Sites



Figure 3: Googlemap of AMPATH Sites

Source: <http://medicine.iu.edu/ampathresearch/index.php/about-research/ampath-sites/>

Download date 28/05/2012

## Appendix V: Approval letter from IREC



MOI TEACHING AND REFERRAL HOSPITAL  
P.O. BOX 5  
ELDORET  
Tel: 3347142/3



MOI UNIVERSITY  
SCHOOL OF MEDICINE  
P.O. BOX 4606  
ELDORET  
Tel: 3347142/3

**INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)**

Reference: IREC/2008/88  
**Approval Number: 000409**

30<sup>th</sup> June, 2009

Kaguiri C. Eunice,  
Moi University,  
School of Public Health,  
P.O. Box 4606,  
ELDORET.

Dear Ms. Kaguiri,

**RE: FORMAL APPROVAL**

The Institutional Research and Ethics Committee have reviewed your research proposal titled:

***"Effects of Social Support on Adherence to Antiretroviral Therapy among Patients Attending AMPATH Clinic at Moi Teaching and Referral Hospital"***

Your proposal has been granted a Formal Approval Number: **FAN: IREC-000409** on 30<sup>th</sup> June, 2009. You are therefore permitted to continue with your study.

Note that this approval is for 1 year; it will thus expire on 29<sup>th</sup> June, 2010. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to expiry date.

You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change (s) or amendment (s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Yours Sincerely,

*for* **PROF. D. NGARE**  
**CHAIRMAN**  
**INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE**



cc: Director - MTRH  
Dean - SOM  
Dean - SPH  
Dean - SOD

**Appendix VI: Permission letter from AMPATH-Research Office.**



USAID | AMPATH  
PARTNERSHIP



Academic Model Providing Access To Healthcare  
P.O Box 4606 ELDORET  
**RESEARCH OFFICE**

Ref: RES/STUD/9/2009

July 20, 2009

To: Modules 1, 2 & 3.

In Charge,

**RE: PERMISSION TO CONDUCT RESEARCH AT AMPATH**

This is to kindly inform you that Eunice C. Kaguiri (SPH/PGH/20/07), Master of Public student at Moi University School of Public health has been granted permission to conduct research at AMPATH Modules 1, 2 & 3. Her study; "*Effects of Social Support on Adherence to ART among patients attending AMPATH clinic at MTRH*" has been reviewed by IREC and assessed by the Research Office. The supervisors are Dr. Edwin Were, and J.B Balidawa

Her research activities should not in any way interfere with the care of patients. This approval does not support access to AMRS data at AMPATH.

The researcher is to submit a final report of his findings to the AMPATH research office and to the departments concerned.

Should the researcher wish to publish her findings, permission has to be sought from AMPATH Publications Committee. Please contact the Research Office in case of any enquiry regarding this matter.

Thank you,

J. Kisuya

Ag. Research Manager, AMPATH

CC.

- Program Manager, AMPATH
- Associate Program Manager Research
- In charge psychosocial Support, AMPATH