SOCIAL SUPPORT FACTORS INFLUENCING ADHERENCE TO ARV AMONG PATIENTS ATTENDING KISII LEVEL FIVE HOSPITAL

BY

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DECLARATION

Declaration by the Candidate

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DEDICATION

I would like to dedicate my thesis to my beloved family members and friends for their invaluable support and encouragement.

ABSTRACT

Background: Antiretroviral adherence is the second strongest predictor of progression to AIDS and death, after CD4 count. The average rate of adherence to ART is approximately 70%, despite the fact that long-term viral suppression requires near-perfect adherence rate. Achieving such high rates of adherence is very challenging to patients due to a range of factors but more so on social support related factors. This study sought to investigate the influence of social support factors to ART adherence and the underlying factors.

Methods: A cross sectional study involving 333 adult HIV clients enrolled on ART for more than three months in Kisii Hospital. The clients were selected through systematic sampling and data was collected using interviewer administered questionnaire. Two homogeneous focus group discussions for men and women were conducted. Data from interviewer administered questionnaire was cleaned, coded and entered into Statistical Package for Social Scientists (SPSS) version 11.5 and analyzed for frequencies, cross-tabulations and Chi-Squared test at statistical significance set at $p<0.05$. Qualitative data from focus group discussion was translated, transcribed and coded through listing and organization of the data under key thematic areas derived from the objectives.

Results: Seventy percent (69.7%) of the respondents were females while 30% were males. Among all respondents, 49.2% were married with more females at 25.8% married as compared to men at 23.4%. The mean age of the patients was 37.7 years with a range of between 21- 63 years. About 40.8% of the respondents had attained secondary or post secondary education. Eighty percent (79.9%) of the respondents took drugs according to the prescribed time. The most cited reasons for missing the timing of the drugs were forgetting 13.2%, being busy 6% and being away from home 3%. Main social support factors that were found to significantly influence adherence based on timing of taking drugs included membership to CBO ($p=0.002$) and disclosure to close family members who included brother ($p=0.02$) and sister ($p=0.014$). The study found high knowledge levels that significantly affected adherence ($p=0.001$).

Conclusion: Adherence rates were found to be relatively high and key social support variables that were found to be significantly associated with adherence were disclosure and membership to CBO. Other key factors affecting adherence include forgetting, being too busy, being away from home and lack of transport.

Recommendations: PLWHIV should be facilitated to join existing community groups so as they can discuss and interact together with the rest of community members as this can greatly help and motivate them in their treatment and adherence. Disclosure being an entry point to social related support for PLWHIV, there is need to scale up couple and family counseling sessions as well as support initiatives that are geared towards reducing stigma and discrimination to PLWHIV.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ACRONYMS

AIDS	Acquired Immuno Deficiency Syndrome
AMREF	Africa Medical Research Foundation
ARC	Aids Related Complex
ART	Anti-retroviral Therapy
ARV	Anti-retroviral drug
CBO	Community Based Organization
DASCO	District Aids and STI Coordinator
DOT	Directly Observed Treatment
FGD	Focus Group Discussion
GoK	Government of Kenya
HIV	Human Immunodeficiency Virus
HAART	Highly Active Antiretroviral Treatment
IREC	Institutional Research Ethical Committee
MERLIN	Medical Emergency Relief International
NGO	Non Governmental Organization
PLWHIV	People Living With HIV
SPSS	Statistical Package for Social Sciences

OPERATIONAL DEFINITION OF KEY TERMS

Adherence

Adherence is defined as taking ARVs (HAART) according to prescribed dosage and frequency. While there may be no gold standard with which to measure adherence, adherence may be measured by a variety of strategies such as self reports (including surveys, interviews and diaries), clinical assessments, pill counts and Directly Observed Therapy (DOT). In this study, self-reports of patients was used to assess adherence rate with the main indicator being correct timing of taking drugs.

Social Support

Social support is defined as the degree to which HIV clients are socially integrated to access individuals, groups/networks and institutions for help in meeting their ART needs. In this study, key social support variables investigated included disclosure, support group membership, CBO membership, women group membership, men group membership and treatment supporter.

CHAPTER ONE

INTRODUCTION

1.1 Background information

HIV and AIDS still remains a major public health problem globally but more specifically in Sub Saharan Africa where 90% of all the cases in the world are reported. In Kenya HIV/AIDS has become a significant public health challenge and poses a serious problem in the country's health care delivery system. The virus was first diagnosed in Kenya in 1984 and by 1993 39,000 HIV/AIDS cases had been reported [1]. Since then, there have been deaths and untold suffering. Although there is no cure, treatment exists that has transformed this condition from an acutely lethal infection into a manageable chronic illness.

In Kenya, by November 2007, over 178,000 people had access to Antiretroviral treatment through accredited treatment centre's (both public and private treatment centre's) [2]. It is estimated that there will be an increase by 10% each year of the patients who require ARV [2]. However, for successful treatment of HIV and AIDS, it requires high rates of adherence to prescribed medications.

Although there is no universally accepted definition, ART adherence may be defined as the extent to which a patient takes a medication in the way intended by a health care provider [3]. Antiretroviral adherence is the second strongest predictor of progression to AIDS and death, after CD4 count. Non-adherence to treatments can take a number of forms which may include not attending or coming late to appointments, not initiating a recommended treatment, not taking medication as prescribed (e.g. taking too many drugs or too few pills, taking medication at incorrect

times) and terminating the treatment prematurely. The average rate of adherence to ART is approximately 70%, despite the fact that long-term viral suppression requires near-perfect adherence (100%).

Both patients and health care providers face significant challenges with respect to adherence to ART. Once on ART, is a life long treatment that consists of multiple medications to be taken two or three times a day with varying dietary instructions. These medications also have side effects, some of which may be temporary while others may be permanent requiring a change of treatment.

The consequences of non-adherence, however, are felt by both the patient and the community. Not only will the infected individual's health deteriorate, but as a result resistant forms of the HIV would exist. On a community scale, the dangers of drug resistant strains of HIV are immense. The results of ineffective drugs will cost the community both financially and in terms of health. Therefore to obtain maximum benefit from the current antiretroviral medication it is required that those on it are fully responsible to ensure complete compliance to treatment.

Living alone and lack of support have been associated with an increase in sub-optimal adherence and social isolation is predictive of suboptimal adherence [3]. Not living alone, having a partner, social or family support, peer interaction, and better physical interactions and relationships are characteristics of patients who achieve optimal adherence [4].

Baum and Nesselhof [5] mentions the need to examine social support as a mediator of stress, because social support has been found to be less available to those on ARV treatment, as a result of AIDS related stigma. The result is an increase in stress levels and perhaps a decreased adherence. For this reason, available social networks and their effectiveness should be explored in relation to ART adherence.

1.2 Statement of the problem

Imperfect adherence to antiretroviral treatment is posing a major challenge to effective management of care and treatment to HIV and AID patients. Inadequate adherence to treatment has been associated with detectable viral loads, disease progression, episodes of opportunistic infections and poor health outcomes [6, 7]. Although social support has been extensively examined in patients with cancer and other catastrophic or chronic illness, it has been examined to a lesser degree with regards to antiretroviral adherence among HIV and AIDS clients. Despite efforts by Kisii Level 5 Hospital and other collaborators to implement social support interventions among HIV and AIDs clients, there has been an increase in reported cases of non-compliance to antiretroviral treatment. In the year 2007, the Kisii Central District AIDS and STI coordinator (DASCO) reported that of all the 756 revisits out of 1,872 total cumulative clients on antiretroviral treatment, 166 clients (22%) were as a result of poor medication adherence, which was largely attributed to inadequate support from close family members [8]. This has been associated with poor health outcomes in clients on antiretroviral treatment. It is important to build up some evidence to determine how social support factors affect adherence and successful treatment.

1.3 Justification

Adherence to antiretroviral treatment has emerged as a crucial factor in HIV/AIDS care and treatment. In order to maximize the potential of each drug and drug combination, targeted efforts to increase and maintain high rates of adherence are essential. Patient non adherence to ART continues to be a significant barrier to effective healthcare delivery and literature on the effectiveness of interventions to improve adherence is fairly inconclusive especially in developing countries. While the ministries of Public Health and Sanitation and Medical Services in Kenya with support from other developing partners have instituted a number of interventions to foster adherence to optimal levels, it is effects are not well known. One of the main interventions advocated for, is strengthening the social support system as it is considered cost effective and more sustainable in the long run. However, few studies in developing countries and notably Kenya have been conducted to demonstrate the influence of this intervention in relation to contributing to optimal adherence rates. It is from the foregoing that this study was designed to explore the role of social support system in promoting optimal adherence rates.

The choice of Kisii level Five Hospital as the study site was based on the fact that the hospital is one of the high volume patient sites in Nyanza province in terms of ART service provision to eligible clients. In addition, the magnitude of adherence in relation to social support factors is not well documented despite the hospital instituting a number of interventions aimed at increasing adherence rates.

The study aimed to show associations between adherence to antiretroviral treatment and social support factors. The findings from the study are meant to be used by health

care and social workers in the design of interventions that aim at ensuring positive health outcomes for clients who are on antiretroviral treatment. In addition, the findings from the study will enable health professionals especially the physicians and nurses to accurately predict whether a person will adhere or not adhere to antiretroviral treatment.

1.4 Research Objectives

General Objective

To determine the influence of social support factors to ART adherence and to investigate underlying factors.

Specific objectives

1. To determine the rate of ART adherence among patients enrolled in comprehensive care centre.
2. To identify social support factors which influence rate of ART adherence.
3. To determine the level of knowledge on antiretroviral treatment and how it affects the rate of adherence.

1.5 Research questions

1. What is the rate of adherence to ART treatment among HIV clients in Kisii Level Five Hospital?
2. What are the social support factors that affect adherence to ART?
3. What is the level of ART knowledge and how does it affect the rate of ART adherence?

CHAPTER TWO

LITERATURE REVIEW

2.1 Overview of HIV/AIDS disease burden

The HIV pandemic remains the most serious of infectious disease to public health globally. The estimated number of persons living with HIV worldwide in 2007 was 33.2 million [30.6–36.1 million], a reduction of 16% compared with the estimate published in 2006 of 39.5 million with a range of 34.7–47.1 million [9]. Examination of global and regional trends suggests the pandemic has formed two broad patterns: generalized epidemics sustained in the general populations of many Sub-Saharan African countries, especially in the southern part of the continent; and epidemics in the rest of the world that are primarily concentrated among populations most at risk, such as men who have sex with men, injecting drug users, sex workers and their sexual partners [9].

Sub-Saharan Africa is one of the most affected regions with the HIV epidemic. The region's epidemics, however, vary significantly in scale, with national adult (15–49 years) HIV prevalence ranging from less than 2% in some countries of the Sahel to above 15% in most of southern Africa [9]. Although percentage prevalence has stabilized, continuing new infections (even at a reduced rate) contribute to the estimated number of persons living with HIV of 33.2 million [9]. More than two out of three (68%) adults and nearly 90% of children infected with HIV live in this region, and more than three in four (76%) AIDS deaths in 2007 occurred in the region illustrating the unmet need for antiretroviral [9].

The first identified case of HIV in Kenya was recorded in 1986 [10].While the highest rates of infection were initially concentrated in marginalized and special risk groups, for more than a decade Kenya has faced a mixed HIV/AIDS epidemic; new infections are occurring in both the general population and vulnerable, high-risk groups. In 1999, the Government of Kenya (GoK) declared the HIV epidemic a national disaster and established the National AIDS Control Council (NACC) to coordinate the multisectoral response to HIV/AIDS [10]. Through support from other development partners, NACC has been able to spearhead HIV response through implementation of HIV prevention, care and treatment programs in the country. In order to sustain the gains made within the care and treatment program, it is critical to ensure patients adhere to treatment regimens as prescribed by health professionals. In order to support this initiative, there is need to build a knowledge of evidence on what interventions or strategies that enhance ART adherence rates. The current study will be relevant in contributing to this body of knowledge by investigating how social support factors influence adherence rates.

2.2 Adherence rate and it is measurement.

The introduction of highly active antiretroviral therapy (HARRT) has shown to reduce the progression of HIV/AIDS and prolong life [11]. HIV-infected individuals on ART have shown to increase life expectancy by 10-12 years in comparison to non-HAART treatment [12]. Treatment efficacy relies, however, on sustained adherence, which constitutes a serious challenge to those receiving ART [13]. Antiretroviral treatment requires a near perfect adherence rate; below this rate the therapy has shown to be inadequate for sustained viral suppression [13]. Therefore, substandard adherence is harmful, not only to the individual but also to public health. For the

individual, decreased adherence rate has shown to increase side effects, reduced viral suppression, deteriorating immune system and ultimately a low quality of life [7]. Furthermore, the reduced therapy load will allow proliferation of multidrug-resistant strains of the virus and if others were to be infected then it will become a serious public health problem.

Measurement of adherence is imperfect and currently lacks established standards. While patient self reporting of complete adherence has been an unreliable predictor of adherence, a patient's estimate of suboptimal adherence is a strong predictor [7]. Since adherence is very individual and personal there is no single variable that can pinpoint the root of non-adherence. Adherence to HIV medications has been well studied, however the determinants, measurements, and interventions to improve adherence to antiretroviral therapies are insufficiently characterized and understood [7]. In a meta analysis study on adherence to antiretroviral therapy in North America (28 full-text articles and 3 abstracts) and 27 studies 9 full-text articles and 18 abstracts) from sub-Saharan Africa 71% used patient self-report to assess adherence in North America while 66% used self reports in sub-Saharan Africa [14]. The studies reported similar thresholds for adherence monitoring (e.g. 100%, _95%, _90%, _80%). A pooled analysis of the North American studies (17 573 patients total) indicated a pooled estimate of 55% (95% confidence interval, 49%-62%; I2, 98.6%) of the populations achieving perfect adherence rates in comparison to a pooled estimate of 77% (95% confidence interval, 68%-85%; I2, 98.4%) in the African studies (12,116 patients total) [14]. This adherence rates are similar to a study among 445 pregnant women receiving antiretroviral drugs which recorded an adherence rates of 75% during the four days before their study visit nearest to but before delivery

[15]. This contrasts findings from a cross sectional study on factors affecting antiretroviral drug adherence among HIV/AIDS adult patients attending HIV/AIDS clinic in Eldoret that showed only 43.2% adhered to the prescribed time of taking drugs [16]. This illustrates differentials in adherence rates defined by different settings and environments. This calls for research studies in specific set ups so as to inform the needs of particular targeted populations. The present study is crucial in determining adherence rates within Kisii region of Nyanza province.

2.3 Factors that influence adherence

Knowledge of HIV treatment is a variable that has been studied in the past in relation to adherence. A review article by Mehta [7], reports that patient non-adherence is significantly associated with the patient not knowing the correct dose of medication or that chronic medications have to be taken continuously. The article shows further that lack of treatment knowledge has led individuals to discontinue treatment due to a positive response or due to a delayed clinical response. Though this study is dated in terms of HIV treatment advances, it outlines problems associated with patients of limited therapy knowledge.

In a study by Wood and Koopman [11] to improve the understanding of the relationship between socio-demographic characteristics and HIV treatment adherence, the researchers found that “patients diagnosed with AIDS, older in age and receiving a higher income were more likely to keep medical appointments while African American men identified as heterosexual were associated with missing scheduled medical appointments”.

In a similar study on factors affecting antiretroviral drug adherence among HIV/AIDS adult patients attending HIV/AIDS clinic in Eldoret [16], most of the reasons cited for missing prescribed dosing time by the patients were: Being away from home 68.8%, being too busy 58.9%, forgetting 49.0%, having too many medicines to take 32.6% and stigma attached to ARVs 28.9%. Though the studies have investigated factors at the patient level, little is mentioned with regards to factors within the health care system The current study will explore a number of factors within the health care system with a view to illustrate on how they contribute to adherence rates.

2.3.1 Social factors that influence adherence

In an article by Gonzalez [17], two specific variables, that is, family support and positive states of mind were addressed with regard to HIV treatment adherence in men and women. The investigators found a positive correlation between family support, positive mind state and adherence to HIV treatment.

Donlou, Walcott, Gottlieb, and Landsverk [18] studied the influence of social support on the well being of 21 men with AIDS related complex (ARC) and AIDS. They measured the number of social relationship and the amount of social support perceived by the subjects in each of their relationships. Although respondents scores on social support ranged widely, as a group they reported mothers and close friends as important sources of social support. With regard to changes in social relationships after diagnosis respondents reported a decreased frequency of social contacts. Reasons for decreased social contacts included friends being fearful and thus avoiding contact and respondents concern with trying to avoid their diagnosis from others. The researchers found that social support was negatively correlated with depression, and

that support from a spouse-lover in particular was strongly correlated with self esteem.

Beckham [19] reinforced the importance of social support with HIV impacted individuals in his description of group work with this population. Support groups can be used for problem solving type's support, such as sharing information about doctors, treatments, and favourite personnel remedies. According to Herek & Glunt [20], AIDs related stigma could conceivably cause patients to lose their jobs and perhaps even to lose their homes because of pressure they may sense from their communities. The enforced social isolation that an HIV impacted individual may experience is virtually unparelled. One cannot help but view social support as a primary concern to address with all HIV impacted individuals. Studies have shown that women as a group may be affected by social support differently from men [21] and these differences may have implications for HIV positive women who are using support services. Women in general have been shown to use more social support than men [22]. Also the type of social support used by women may be of more intimate and self disclosing nature, which may be more adaptive in reducing distress than the more task oriented or activity oriented types of relationship men are often socialized to prefer Studies by Troll [23] as well as by Neighbor and Jackson [24] reported that women (particularly black women) have stronger kin networks and are less isolated than men.

Kaplan and Hartwell [25] examined the effects of social networks on adherence to a medical regimen for diabetes management in men and women. The researchers found that high levels of social support were associated with greater compliance to the

medical regimen from the women, but with less compliance from men. This suggested that men socials networks may reinforce behaviors not in their best interest, whereas women's network was more likely to encourage appropriate self care.

Role of social support in HIV-infected drug users was studied by Broadhead [26]. The theory basis of this study was focused around the peer-driven intervention and its effects on HIV treatment adherence. This theory centers on the idea that all social behavior is rooted in inclinations and regulatory interests. The author defines inclination as "individual's preferences regarding how they would like themselves to behave," and regulatory interests as "individual's preferences regarding how they would like others to behave." By manipulating these to influence with other immediate incentives, the researchers found a positive influence of regulatory interests on adherence that influenced inclination.

Despite social support being described as a key predicator of good adherence rates, little is mentioned on how the different elements affect adherence rates. There is a need to determine the influence of the different types of social support and how they affect adherence rates. This would be important in informing program managers on the appropriate social support interventions in different settings. The current study will attempt to address this area.

Conclusion

The literature review points towards health service factors, social support factors and psychological stress and knowledge as few of the barriers to a perfect adherence rate. However the literature does not categorically quantify to what extent these factors influence adherence rates.

CHAPTER THREE

METHODOLOGY

3.1 Study setting

The study was conducted at Kisii Level Five Hospital in Kisii Central District of Nyanza province in southwest of Kenya. The District covers an area of about 648.9 square Kilometers with an average population density of 757 persons per square kilometers. The district is divided into seven administrative divisions namely, Suneka, Marani, Masaba, Mosocho, Keumbu, Kiamokama and Kiogoro with 31 Locations and 92 Sub-Locations. The leading causes of mortality and morbidity in Kisii central district are related to malaria, HIV and AIDS, pneumonia, TB, injury, measles, protein calorie malnutrition and diarrhea. The HIV prevalence in the district is approximated at 7%, with approximately 6,429 adults and 514 children requiring Anti Retroviral Therapy (ART).

The hospital is one of the referral facilities in the province and the catchment population is approximated to be 299,830.It is one of the high voluminous health facilities in the region with an established HIV and AIDs Comprehensive Care Clinic.

3.2 Study population

The study population comprised of all adult patients (>18 years based on the definition of an adult by the Kenyan law) who attended Comprehensive Care Clinic in Kisii Level Five Hospital for antiretroviral treatment. By the end of September 2009, 5,685 clients were enrolled at the clinic out of which 3,726 patients were on ART. Averages of 105 clients attend the clinic on a daily basis and are served by two clinicians. The clients are taken through health education sessions on nutrition, adherence, and adverse effects of drugs among others.

A total of three hundred and thirty three (333) adult patients were recruited into the study after informed consent was sought from them. They were interviewed as they came for treatment at the clinic by use of a structured closed ended and open ended interview schedule. The research assistants worked in close collaboration with the clinicians in identifying clients who have been on ARV treatment for at least three months. Twenty caregivers and close family members affiliated to the interviewed clients were recruited and participated in two focus group discussions for males and females.

3.3 Study design

A cross-sectional study design was used in the study by use of quantitative and qualitative methods. The key variables examined were: demographic characteristics, adherence attributes, socio support factors and patient and drug related factors.

3.4 Sample size determination

Though patients presented to the hospital for drug refills, it was not possible to determine perfect adherence rates in the target population and therefore a probability of 0.5 was used to compute the sample size. Setting the confidence level at a 95% and the sampling error at 5%, the sample size was obtained using the Fischer's formula below [27].

$$n_o = \frac{Z^2 \text{ X } p\,(1-p)}{d^2}$$

$$= \frac{1.96^2 \text{ X } 0.5\,(1-0.5)}{0.05^2}$$

n_o = **384**

Given that the target population (N) at the facility was small (3,726), the sample size n_o was adjusted by the formulae below.

$$n = \frac{n_o}{1 + \frac{(n_o - 1)}{N}}$$

$$= 348$$

Where;

N=Desired sample size

Z=Standard normal deviate of required confidence level

d=Statistical significance level

p=Prevalence of the characteristic of interest

n_o =calculated sample size

3.5 Sampling procedure

The study applied systematic sampling method in recruiting respondents into the study. A calculated number (10^{th}) derived from dividing the total population in the sample frame (3,726) with the calculated sample size (348) was the first respondent to be interviewed and thereafter every 10^{th} client was interviewed after being seen by the clinician. At the end of the study, a total of 333 adult HIV clients were interviewed. This was lower than the calculated sample size of 348 which was a result of limited time for data collection. The 333 sample size was deemed to be adequate for statistical analysis. Participants for the focus group discussion (family members/caregivers) were recruited by requesting the interviewed respondents to propose a family member or caregiver to participate in the focused group discussion at a later specified date. The recruitment process alternated between males and females to ensure there is gender balance. A total of 20 participants (10 males and 10 females) were recruited to participate in separate men and women focus group

discussions. The FGDs were conducted at the community level and was facilitated in the local language. Proceedings for the FGDs were recorded manually as well as using an audio tape recorder. An FGD guide was used to guide the discussions.

3.6 Inclusion criteria for interviews

- People Living with HIV receiving antiretroviral treatment at comprehensive care centre for the last three months.
- Over 18 years (People Living with HIV).
- Strong enough to sit and talk for an interview.
- Willingness to participate in the study.

3.7 Exclusion criteria for interviews

- Clients who were too sick to sit for an interview.
- Unwillingness to participate in the study.
- Below 18 years.

3.8 Inclusion criteria for FGD

- Caregivers and family members >18 years

3.9 Data collection tools

The study applied two sets of research instruments to capture the requisite information, which included an interview schedule questionnaire for adult HIV positive clients and an FGD schedule for family members/caregivers.

The interview schedule questionnaire included sections on: Demographic characteristics, socio support factors, adherence attributes, knowledge, beliefs and perception on ART, patient and drug related data. The interview schedule was accompanied with side notes to guide research assistants in the skipping patterns of the questions. During the training session for the research assistants, the tool was translated from English into the local language (Ekegusii) and back translated in original English texts to ensure the questions elicit the same response. In the scenario where there was a difference, this was rectified in the English version. The FGD guide was used to gather information from family members/caregivers on their perception, practices and behavior towards ARV clients at the community level. Men and women participated separately in the focus group discussions that were facilitated in the local language.

3.10 Data collection procedures/Field preparations

Phase 1: Pre-test

Prior to collection of primary data, two research assistants were recruited and taken through two day training on the tools as well as on key elements of the study protocol. The research assistants were diploma graduates in clinical medicine and community health. After the training, the tools were pre-tested at Nduru Sub-District hospital. The hospital was chosen due to it is comparability with Kisii Level Five hospital in terms of the services provided and clients served. A total of 10 respondents were interviewed in the pilot study and the data collected was analyzed, interpreted and there on the tools were reviewed and made ready for data collection.

Phase 2: Main survey

Prior approval was sought from the hospital administration to conduct the study at the Kisii level five hospital comprehensive care centre. Respondents were sampled by use of systematic sampling after seeking appointment from the clinicians. Respondents were duly informed about the general nature, purpose of the study and their rights to withdraw at any time without prejudice. Subsequently, the respondents were required to either sign on the data collection tools or thumb print as a sign of having given their consent for participation in the study.

The principal investigator randomly sampled the completed questionnaires to check that answers to all questions were correctly recorded and that skip patterns were correctly followed as specified in the questionnaire guide. Each day prior to the data collection process, there was a debriefing session to share feedback from the supervisor and research assistants.

The actual data collection for this study took 2 months, from 27/10/2009 to 23/12/2009. Data collection was done between 9 am to 3 pm daily with an average of 12 respondents interviewed per day. Probing was done to ascertain accuracy of answers given by respondents. Completed questionnaires were cross checked to ensure all questions are answered correctly.

3.11 Data analysis

Quantitative: - Each question in the interview schedule questionnaire was assigned a variable. The responses to each question were categorized and assigned numerical codes that differentiated the various response categories for each question. Data was

keyed into Statistical Package for Social Sciences (SPSS) version 11.5. The quantitative data analysis focused on identifying rates of ARV adherence, socio-support systems, reasons for non-adherence and knowledge and perceptions related to antiretroviral. Additional analyses examined relationships between ARV adherence, socio support systems and demographic indicators. Analysis performed included frequencies, central tendencies i.e. mean and cross-tabulations. Statistical significance was set at $p< 0.05$ for chi-square.

Qualitative: - The qualitative data collected through focus group discussions were translated, transcribed, and analyzed through listing and organization of the data under key thematic areas derived from the objectives. The derived themes were compared across genders. Relevant verbatim excerpts were identified, extracted and used in the report.

3.12 Ethical considerations.

The study was reviewed and cleared by Institutional Research and Ethics Committee (IREC) from Moi University/Moi Teaching and Referral Hospital. Thereafter permission was sought in writing from the medical superintendent in charge of Kisii Level Five Hospital to carry out the study in the facility. A written informed consent statement was also included on the introductory part of the interview schedule that further explained the study purpose and confidentiality of the study information. The interviews were conducted in a secluded place to avoid distraction and maintain confidentiality and privacy. During the FGD, the participants were made aware that other participants will be able to listen to their contributions however all the participants were requested not to tell others what they are going to hear from the

discussion. Data security was ensured by use of coded information, which was only available to the investigator. Similarly, names of the respondents were not recorded anywhere in the data collection tools.

3.13 Study limitation

The technique used for assessing adherence was client self reports by use of a questionnaire which may affect it is sensitivity. In order to address this, the research assistants were trained on how to create a more comfortable and trusting environment in which the patients would honestly report on adherence rates.

-Limited time during data collection period that resulted to non-attainment of the calculated sample size.

CHAPTER FOUR

RESULTS

Section 1: Survey Findings.

4.1 Background characteristics of the study population

A total of 333 People Living with HIV attending comprehensive care clinic in Kisii level 5 hospital were interviewed in a period of 2 months from 27/10/2009 to 23/12/2009 between 9 am to 3 pm daily. There were more females (69.7%, n=232) than males (30.3%, n=101). Fifty percent of the respondents were married (49.2%, n =164) with more females married (25.8%, n=86) as compared to men (23.4%, n=78). A majority of the patients were in the age groups of between 38 - 42yrs (14.7%, n=49), 18 - 22 yrs (14.4%, n=48) and 28 - 32 yrs (14.1%, n= 47). The mean age of the patients was 37.7 years with a range of between 21-63 years. Two thirds of the respondents (65.5%, n=218) resided outside Kisii municipality while 40.8% of the respondents had attained secondary or post secondary education. More than a third of the patients (35.4%, n=118) were unemployed with more females affected than males. Similarly a majority of the respondents (92.2%, n=307) were living with relatives back at their homes. More than a third of the respondents (36%) had been in the ART program for between 4 and 12 months. Similarly, 46.2 % of the respondents had been in the program for between 2 and 3 years and 17.7% were in the program for between 4 and 6 years. The average length of time in the ART program was 2 years with a range of 4 months to 8 years. A majority of the respondents (91.9%) came by themselves to the clinic while 8.1% of the respondents were accompanied by either spouse, friends or parents/guardians.

Table 1: Background characteristics of respondents.

Characteristic		n	%
Age	18-22	48	14.4
	23-27	34	10.2
	28-32	47	14.1
	33-37	28	8.4
	38-42	49	14.7
	43-47	45	13.5
	48-52	38	11.4
	53 +	44	13.2
Gender	Male	101	30.3
	Female	232	69.7
Marital status	Single	57	17.1
	Married	164	49.2
	Divorced	6	1.8
	Widowed	105	31.5
	Separated	1	.3
Occupation	Formal	31	9.3
	Informal	184	55.3
	Unemployed	118	35.4
Education	None/Primary	197	59.2
	Secondary/Post Secondary	136	40.8
Residence	Kisii Municipality	115	34.5
	Outside Kisii Municipality	218	65.5

4.2 Rate of adherence to use of anti-retroviral drugs

Eighty percent of the respondents (79.9%) had a perfect adherence rate that was based on correct timing of taking drugs. A higher proportion of females (82.8%) had a perfect adherence rate as compared to males (73.3%).The study found marginal difference (p=0.054) between males and females as relates to adherence rates.

Table 2: Adherence rates based on timing of taking drugs.

		Perfect Adherence Rate	Imperfect Adherence Rate	Total	
Sex	Male	74 (73.3%)	27 (26.7%)	101(100%)	χ^2 =3.944
	Female	192 (82.8%)	40 (17.2%)	232 (100%)	P =0.054
Total (Count)		**266**	**67**	**333**	
Total (%)		**79.9%**	**20.1%**	**100%**	

Most of the patients with perfect adherence rate were in the age bracket of 38 - 42 years (16.5%, n=44). Fifty percent (49.6%, n=132) of the respondents with perfect adherence rate were married as compared to 28.9% (n=77) who were widowed and 18.8 % (n=50) who were single. The respondents who had none or primary education (59.8%, n=159) had a perfect adherence rate. Those who lived outside Kisii Municipality (62.8%, n=167) had a perfect adherence rate.

A majority of the patients with an imperfect adherence rate were in the age bracket of 43-47 years (19.4%, n=13) and over 53 years (19.4%, n=13). Similarly fifty percent of the clients (49.3%, n=33) with an imperfect adherence rate were unemployed. Some of the factors cited as contributing to imperfect adherence included forgetting (64%), being busy (29.9%) and being away from home (14.9%).

Among the background characteristics, the study found significant differences on adherence rates with occupation of the clients (p=0.03) and the residence of the clients (p=0.04).

Table 3: Adherence rates according to Socio-demographic characteristics.

Background characteristic		Perfect Adherence Rate		Imperfect Adherence Rate		χ^2 **statistic**
		n	**%**	**n**	**%**	
Age Category	18-22	42	15.8	6	9.0	$\chi^2 = 10.07$ P= .184
	23-27	26	9.8	8	11.9	
	28-32	37	13.9	10	14.9	
	33-37	22	8.3	6	9	
	38-42	44	16.5	5	7.5	
	43-47	32	12.0	13	19.4	
	48-52	32	12.	6	9	
	53 +	31	11.7	13	19.4	
Educational Level	None/Primary	159	59.8	38	56.7	$\chi^2 = .207$ P= .649
	Secondary/Post Secondary	107	40.2	29	43.3	
Residence	Within Kisii Municipality	99	37.2	16	23.9	$\chi^2 = 4.211$ P= .040
	Outside Kisii Municipality	167	62.8	51	76.1	
Marital status	Single	50	18.8	7	10.4	$\chi^2 = 6.780$ P= .148
	Married	132	49.6	32	47.8	
	Divorced	6	2.3			
	Widowed	77	28.9	28	41.8	
	Separated	1	.4			
Occupation	Formal employment	26	9.8	5	7.5	$\chi^2 = 7.003$ P= .030
	Informal employment	155	58.3	29	43.3	
	Unemployment	85	32.0	33	49.3	

4.3 Existing forms of social support.

Key social support variables investigated in the study included, disclosure, family unit, membership to support group (comprised of people living with HIV), membership to any other social group in the community i.e. CBO, women's group, men's group and if the respondent was being supported in taking his/her medication. Disclosure as a key determinant to accessing other social support functions for HIV and AIDS clients, the study sought to find out the disclosure status among the respondents to their close relatives and how they interact with the various social support systems. A majority (93%) of respondents had disclosed their HIV status to

their spouses and a further 37.3% had disclosed their status to their father. Almost a half of the respondents had disclosed their HIV status to their mothers, whereas 56.4% of the respondents had disclosed their HIV status to their brothers. Only 27 % of the respondents had disclosed their status to friends.

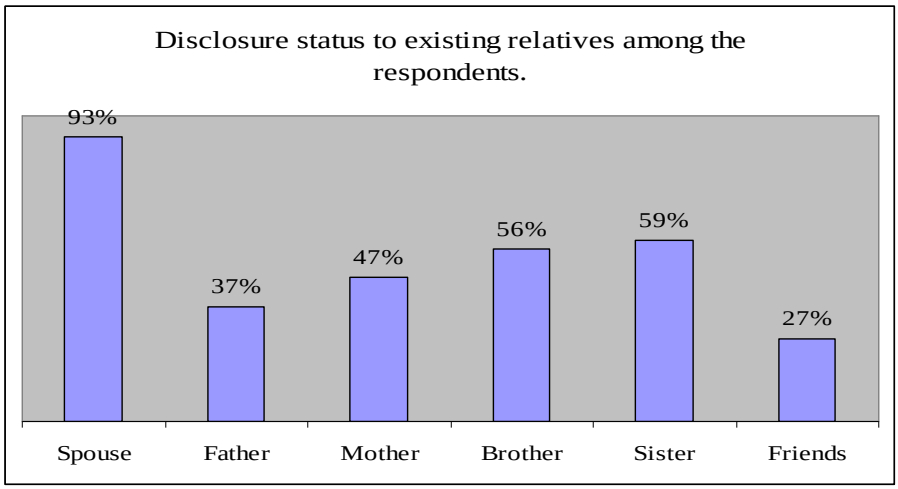

Figure 1: Proportion of respondents who had disclosed their HIV status to close family members.

Findings on other social support variables showed that a majority of the respondents 307 (92.2%) were living with at least one close family member. The average family members' living with the respondents was 5 members. Among all respondents in general, 58%, n=193 were members of a Community Based Organization (CBO) and 50.5%, n=168 belonged to a support group. Among women, 61.2%, n=142 belonged to a women's group whereas among the men 7.9%, n=8 belonged to a men's group. A majority of the respondents (86.2%) reported getting support from close family members and friends in taking their medication.

Table 4: Existing forms of social support systems

Social support factor	n	%
Living with at least one family member.	307	92.2
Membership to CBO	193	58
Membership to support group	168	50.5
Membership to women's group.	142	61.2
Membership to men's group.	8	7.9
Treatment supporter	275	86.2

4.4 Social support factors influencing adherence to ART.

The study sought to find out if social support factors are associated with ART adherence rates so as to inform policy makers and implementers on design of adherence interventions. In the study, significant social support factors found to affect adherence included membership to CBO (p=0.002) and disclosure to close family members i.e. brother (p=0.02) and sister (p=0.014). Membership to a women's group was found to marginally affect adherence (p=0.053).

Men were less likely to engage in social groups as compared to women and there was no significant association between being a member of men's group and rate of adherence.

Table 5: Relationship between social support factors and adherence rates.

Social support factor		**Perfect Adherence Rate**	**Imperfect Adherence Rate**	χ^2 **Statistic**
Membership to CBO	Yes	143 (53.8%)	50 (74.6 %)	$\chi^2 = 9.564$ P= .002
	No	123 (46.2%)	17(25.4%)	
Membership to women's group.	Yes	115 (59.6%)	27 (69.2%)	$\chi^2 = 1.271$ P= .053
	No	78 (40.4%)	12 (30.8%)	
Membership to men's group.	Yes	7 (9.6%)	1 (3.6%)	$\chi^2 = 1.005$ P= .316
	No	66 (90.4%)	27 (96.4%)	
Membership to a support group.	Yes	134 (50.4%)	34 (50.7%)	$\chi^2 = 0.003$ P= .957
	No	132 (49.6%)	33 (49.3%)	
Treatment supporter	Yes	215 (84.6%)	60 (92.3%)	$\chi^2 = 2.555$ P= .110
	No	39 (15.4%)	5 (7.7%)	
Disclosure (Spouse)	Yes	130 (92.2%)	34 (97.1%)	$\chi^2 = 1.079$ P= .299
	No	11 (7.8%)	1 (2.9%)	
Disclosure (Father)	Yes	56 (63.6%)	19 (48.7%)	$\chi^2 = 2.691$ P= .101
	No	32 (36.4%)	20 (51.3%)	
Disclosure (Mother)	Yes	96 (64.9%)	33 (63.5%)	$\chi^2 = 6.771$ P= .678
	No	52 (35.1%)	19 (36.5%)	
Disclosure (Brother)	Yes	139 (53.3%)	45 (69.2%)	$\chi^2 = 5.401$ P= .020
	No	122 (46.7%)	20 (30.8%)	
Disclosure (Sister)	Yes	148 (56.1%)	48 (72.7%)	$\chi^2 = 6.081$ P= .014
	No	116 (43.9%)	18 (27.3%)	

4.4.1 Relationship of ART clients with service providers

Among all the respondents, 94.3% described the waiting time to be acceptable or short before being attended to by the clinician whereas 5.7% of the respondents described the waiting time to be long. Similarly, 92.2% of the respondents described their interaction and communication with the clinician to be good as compared to 1% of the respondents who described the communication as poor or very poor.

4.5 Knowledge of antiretroviral treatment and how it affects adherence.

To ascertain knowledge levels on ART, respondents were asked questions as to whether they think ARVs are beneficial and in their opinion who was eligible and for how long. The study revealed that knowledge of antiretroviral treatment was widespread. Almost all of the respondents 96% (n=319) were of the opinion that antiretroviral treatment was beneficial to their health. A majority of the respondents 96.7% (n=322) knew that antiretroviral treatment was for lifetime with 12.6% (n=42) reporting that HIV persons with lower CD4 count were eligible for antiretroviral treatment whereas 86.5% (n=288) reported that those eligible for antiretroviral treatment are those diagnosed with HIV. A majority of the respondents (88.9%, n=296) had been reached with messages on ART adherence. The common sources of information on ART adherence included sensitization sessions from health care workers (44.7%), radio (13.8%), TV (4.2%) and use of posters/brochures (1.5%). Among the respondents reached with key messages on ART adherence, 60% were of the opinion that this reinforced their adherence related practices.

Knowledge questions that were found to significantly influence perfect adherence rate included, how long should HIV clients be on antiretroviral treatment (P=0.001) and if ARVs were beneficial to the clients (P=0.046).

Table 6: Relationship between knowledge questions and adherence rates.

Knowledge questions		**Perfect Adherence Rate**	**Imperfect Adherence Rate**	**χ^2 Statistic**
Do you think ARVs are beneficial?	Yes	260 (97.7%)	59 (89.4%)	χ^2=3.982 P=0.046
	No	6 (2.3%)	7 (10.6%)	
How long should an HIV+ individual take ARVs?	For life	261 (98.1%)	61(91%)	χ^2 = 24.47 P=0.001
	One year	5 (1.9%)	6 (9%)	
Who should be started on ARVs?	Those with low CD4 count	34(13%)	8 (12%)	χ^2 = 0.810 P=0.847
	Those diagnosed with HIV	229(87%)	59 (88%)	

The study also sought to find out if there were any barriers in the community regarding ART. Among respondents who said there exists barriers in the community on ART, 89% (n=248) cited stigma as a major barrier on antiretroviral treatment. Other perceived barriers included inadequate food, 4% (n=12) and adverse effects from drugs, 7% (n=21).

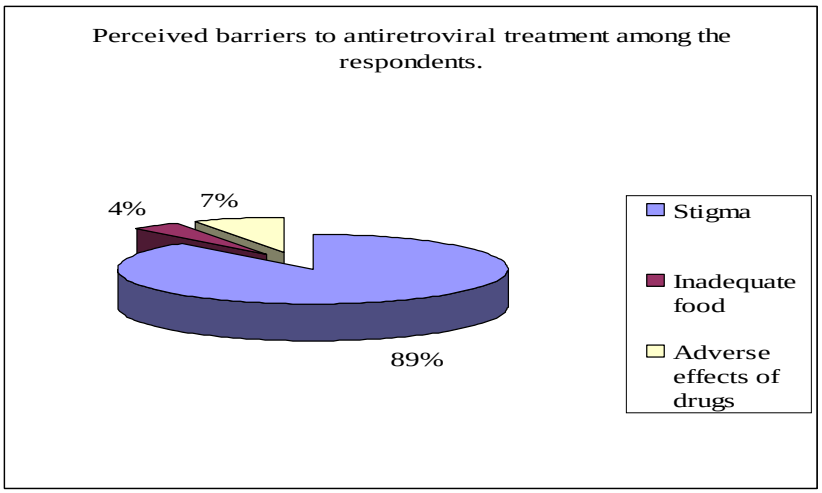

Figure 2: Proportion of respondents who reported on key barriers to antiretroviral treatment.

The study did not find significant associations between the barriers cited and adherence rates.

Table 7: Relationship between barriers and adherence rates

Barrier		**Perfect Adherence Rate**	**Imperfect Adherence Rate**	**χ^2 Statistic**
Stigma	Yes	200 (75.2%)	48 (71.6%)	χ^2=.354 P=0.552
	No	66 (24.8%)	19 (28.4%)	
Inadequate food	Yes	8(3%)	4(6%)	χ^2 = 1.352 P=0.245
	No	258 (97%)	63 (94%)	
Adverse effects from drugs	Yes	16(6%)	4 (6%)	χ^2 = 0.00 P=0.989
	No	250(94%)	63 (94%)	

Section 11: Focus Group Discussions Findings

The focus group discussion process involved two groups of men and women partaking in a discussion in which they were asked to discuss their perception on the rate of ART adherence among the clients they live with. Similarly, the participants

discussed their support and roles to People Living with HIV with regard to enhancing ART adherence.

In all two groups, respondents alluded to the fact that a majority of the clients took their drugs as prescribed by the clinicians. However men reported that some of the clients did not take drugs as prescribed and this was attributed to the fact that some of them are not normally at home and do not carry drugs as they travel. Stigma was also cited as a major factor as to why certain clients do not take drugs as prescribed especially when they are away from their homes.

'' If the clients are away from their homes and in a different environment, some of them will not take the drugs due to the fear that they will be seen by others and their status may be known''

'' Yes, some of the clients travel away from our homes and they do not inform us if they will return the same day or sleep over to where they are going and this makes it difficult for us to remind them''

There were mixed feelings on the extent to which the clients have been integrated within the community. Men reported a low involvement of the clients in the community social network, citing a feeling of not being wanted or recognized by their peers. Others felt that due to the HIV status of the clients, they are viewed as people with loose morals and therefore some of them adopt a self exclusion attitude. However, a section of the women were of the opinion that the clients were well integrated into the community social networks that included support groups, churches, CBOs and women groups. Key benefits cited for being part of these groups included

psychosocial support, material support (Nutrition, school fees, food) and a sense of belonging.

'' They men, do not want to associate with other members of the community and more often than not they are always walking alone in deep thoughts''

'' If you try to talk to some of the clients, they get very angry and therefore we engage them actively if we thinks they are in good mood''

''Previously our clients used not to actively participate in the CBOs and women groups, however overtime they have seen the value of being members in this groups. In some groups the clients have taken up leadership positions and are involved in advocating for more involvement of PLWHIV in various community related work''

''The value to the clients in being part of the social networks include material support e.g. Uniforms to school going children, income and a source of human labour''

As caregivers and family members, they generally felt that in one way or the other, they offered considerable support to the clients as part of enhancing ART adherence. This included counseling and material support (food, clothing). Some of the participants acted as treatment partners as they regularly assisted the clients to take their drugs. Some engaged them in income generating activities and supported them with financial support. It was interesting to note that, the discussants in the FGDs were of the opinion that women were more receptive to being supported at the household level as compared to the men.

'' Personally I supported my sister with capital to open up a small grocery where she is able to get income to cater for her needs. Similarly, we participate in fellowship and prayerful sessions every Saturday''

Both men and women reported that non-disclosure was a major barrier to effective support to PLWHIV with regard to ART adherence. They further said that non-disclosure of the client's status made it difficult for the family members and caregivers to offer adequate support to the clients. On further probing as to whether the family members or caregivers perpetuate stigma and discrimination, some of the participants were of the opinion that was the case and this was related to use of particular phrases to describe the clients e.g. *''watu wa ukimwi''* meaning people with AIDS.

'' To some people in the community, they still view HIV as a curse and consider PLWHIV as outcasts. This attitude makes it difficult to some not disclose their status''

''We normally suspect a person to be HIV+ depending on the frequency of illness''

There was a universal feeling that their still exists myths and misconceptions regarding HIV and AIDS which acted as barriers to effective support in its prevention and treatment. The FGD discussants felt that an open dialogue with their clients played a key role in overcoming such barrier. Some of the myths cited included fear of becoming sterile or sexual inactive for users of ARVs and the belief that the drugs do not work. Stigma was overwhelmingly mentioned as a major barrier and determinant for effective prevention and treatment interventions.

''There are rumours that this drugs causes infertility among men and women and therefore some fear to go for treatment''

CHAPTER FIVE

DISCUSSION

5.1 Overview of adherence rate and it is measurement.

While there may be no gold standard with which to measure adherence rates, patient report is the most commonly used method of assessing adherence in clinical practice because it is relatively quick, easy and expensive. Common methods of obtaining patient report data include questionnaires, daily self monitoring diaries and interviews. Although patient report is the most practical method of adherence assessment, the accuracy of this method is often reduced by patient's hesitance to report non adherence and by limitations in patient's ability to recall past adherence related behavior often resulting in under reporting of non adherence [15]. Despite this limitation, patient report can be a valuable tool and has been found to be a predictor of adherence rates and clinical outcomes [15].

In this study, self-reports of patients were used where timing of taking drugs were used as a key indicator for determining adherence rate.

5.2 Background characteristics of study population

Both male and female respondents were uniformly distributed across the age range 21-63yrs. Almost half of the respondents (49.2%) were married and close to a third (31.5%) of the respondents were widows. Although a high proportion of the respondents reported that they had attended school, levels of unemployment were also high, with more than a third (35.4%) of respondents reporting that they were unemployed. Women were more likely to achieve a perfect adherence rate (82.8%) as compared to men (73.3%).The findings showed that sex, educational level, age and marital status did not significantly affect adherence that was similar to other studies

done elsewhere that have shown little relation between adherence and socio-demographic factors [29]. The findings identified place of residence (p=0.040) and occupation (0.030) to significantly contribute to perfect adherence rates.

5.3 Rate of antiretroviral adherence

Based on timing of taking ARVs, the study found perfect adherence rates to be high for all respondents at 79.9 % an indication of minimal barriers. This was consistent with most ART adherence rates that vary from 22% to 80%, in both clinical trials and clinical practice settings. This was further corroborated by the focus group discussions findings where the respondents alluded to the fact that a majority of the clients took their drugs as prescribed by the clinicians. The high rates of adherence may be attributed to a number of factors derived from the study in the case that a majority of the respondents (92.2) considered their interaction with the clinicians to be good. Similarly, a majority of the respondents (94.3%) were of the opinion that the waiting time at the health facility was acceptable. Key factors reported by the respondents as contributors to imperfect adherence rates included forgetting (64%), being busy (29.9%) and being away from home (14.9%). This was consistent with other studies that have shown that being away from home, being too busy and forgetting are closely inter-related [30] in reinforcing imperfect adherence. Similarly, in the focus group discussions, men reported that some of the clients did not take drugs as prescribed and this was attributed to the fact that some of them are not normally at home and do not carry drugs as they travel. Stigma was also cited as a major factor as to why certain clients do not take drugs as prescribed especially when they are away from their homes.

5.4 Social support factors in relation to adherence rates.

Antiretroviral treatment requires life-long dedication to a healthy lifestyle, medical care and complex drug schedule, a responsibility that no one should have to endure alone and therefore the importance of social support systems to the clients [31]. Findings from the study showed that a majority (93%) of respondents had disclosed their HIV status to their spouses and a further 37.3% father had disclosed their HIV status to their fathers. Almost a half of the respondents had disclosed their HIV status to their mothers whereas 56.4% of the respondents had disclosed their HIV status to their brother. Only 27 % of the respondents had disclosed their status to friends. A further analysis showed that disclosure was significantly associated with perfect adherence rates and more so disclosure to brother ($p=0.02$) and sister ($p=0.014$). The findings were similar to a study that was conducted in Soweto in South Africa that showed how disclosure to family members can have on a patient's ability to consistently take their medication [31]. In a quantitative study [31] on adherence among the same population, it was found that "fear of being stigmatized by sexual partners was independently associated with lower adherence rates". This finding highlights disclosure, specifically to close family members, as a strong factor in overall adherence rate.

On the basis of social groups and networks, the study found out 58%, n=193 of the respondents were members of a Community Based Organization (CBO) and 50.5 %, n=168 belonged to a support group. Among women, 61.2 %, n=142 belonged to a women's group whereas among the men 7.9 %, n=8 belonged to a men's group. This represents low membership of people living with HIV to social networks in this community that may be attributed to the high stigma level witnessed and

demonstrated by the low disclosure rate to friends (27 %). The study found significant association on adherence rates with membership to CBO (p=0.002) while membership to a women's group was found to be marginally significant (p=0.053) This is reinforced by other studies that have shown social networks or groups to be associated with greater compliance to regimens and that women as a group may be affected by social support differently from men [21] and these differences may have implications for HIV positive women who are using support services. Women in general have been shown to use more social support than men [22]. This is further reinforced by the focus group discussion findings where there was mixed feelings among men and women on the extent to which the clients have been integrated within the community social networks. Men reported a low involvement of the clients in the community social network, citing a feeling of not being wanted or recognized by their peers. Others felt that due to the HIV status of the clients, they are viewed as people with loose morals and therefore some of them adopt a self exclusion attitude. However, a section of the women were of the opinion that the clients were well integrated into the community social networks that included support groups, churches, CBOs and women groups.

A majority of the respondents (92.2%) were found to be living with at least one close family member. Similarly, 86.2% of the respondents reported getting support from close family members in taking their medication. The study found marginal significance (p=0.054) on adherence and family support. This is in consistent with a study in an article by Gonzalez [17] on two specific variables i.e. family support and positive states of the mind in relation to HIV treatment adherence in men and women.

The investigators found a positive correlation between family support, positive mind state and adherence rates to HIV treatment.

5.5 Knowledge on ART and how it affects adherence rates.

Knowledge of key elements on antiretroviral treatment is important in reinforcing adherence rates among HIV and AIDs clients. In this study, almost all of the respondents (99.7%) were of the opinion that antiretroviral treatment was beneficial to their health. Similarly, 97.9% of the respondents knew that antiretroviral treatment was lifetime treatment. Less than a quarter of the respondents (12.6%) knew that HIV persons with lower CD4 count were eligible for antiretroviral treatment whereas 86.5% of the respondents reported that those eligible for antiretroviral treatment are those diagnosed with HIV. This showed that basic knowledge on ARV was widespread and advanced knowledge was minimal as illustrated by a low percentage of respondents (12.6%) who correctly reported that ARVs are administered according to an eligibility criteria based on the CD4 count. The general high levels of knowledge may be attributed to the fact that a majority of the respondents (88.9%) had been reached with ART related messages/information. The common sources of information included sensitization sessions from health care workers (44.7%), radio (13.8%), TV (4.2%) and use of posters/brochures (1.5%).

Based on the knowledge questions, the study found significant association with adherence particularly on the question on how long should a HIV client be on antiretroviral treatment ($p=0.001$). A study in an article by Mehta [7] showed that imperfect adherence is significantly associated with the patient not knowing the correct dose of medication or that chronic medication have to be taken continuously. The

article further showed that lack of treatment knowledge lead individuals to discontinue treatment due to a positive response or due to a delayed clinical response.

Stigma was cited as a major barrier to ART by 89% of the respondents which was further corroborated by findings from focus group discussions where it was noted that some clients could not take their prescribed drugs in a different environment due to the fear that they may be seen by others and their status known. Other perceived barriers included inadequate food, 4% (n=12) and adverse effects from drugs, 7% (n=21). The study did not find any significant association between the barriers and the rates of adherence.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The overall adherence rate as evidenced in this study was high with adherence rates of 79.9% among all the respondents.

Several factors have been identified to negatively affect adherence rate to ARVs. In this study, key factors that were found to affect adherence included forgetting, being too busy, being away from home and lack of transport.

In this study, knowledge levels were found to significantly affect adherence ($p=0.001$) whereas stigma was cited as a major barrier to ART adherence.

Lack or inadequate social support has been associated with an increase in imperfect adherence. In this study, key social support factors that were found to significantly influence adherence rates included disclosure, membership to CBOs and women groups. This being the focus of the study, the findings showed that socio support factors were correlated to adherence rate. This implies that it is important to mainstream social support interventions in ART adherence programs so as to achieve perfect adherence rates that are associated to good clinical outcomes.

6.2 Recommendations.

Enhance ART literacy among PLWHIV:- In order to maximize the benefit of ARV therapy, Kisii Level Five hospital in partnership with other partners should enhance it

is education efforts on the need of adhering to taking the right dose at the right time as an intervention against barriers to adherence.

Promote self disclosure among PLWHIV to family members and friends through counseling:- As illustrated from the study, disclosure was found to likely influence adherence rates and whereas the disclosure rates were found to be sub-optimal to a number of groups of people, this need to be given a priority by Kisii Level five Hospital and it is partners as a core intervention. Disclosure being an entry point for social related support for PLWHIV, there is need to scale up couple and family counseling sessions as well as support initiatives that are geared to reducing stigma and discriminations to PLWHIV.

HIV and AIDS targeted educational campaigns aimed at reducing stigma:- Stigma continues to be a concern in the community from HIV-positive people on treatment in Kisii central district. Stigma can lead to the non-disclosure of a clients' HIV status, secretive ART, or even non-adherence to ART. In light of this, Kisii Level five hospital and it is partners should address stigmatization of PLWHIV through community education forums.

Facilitate and support formation of community groups as a mechanism to enhancing social support for PLWHIV:- A majority of the respondents did not belong to community groups such as CBOs, women groups and support group. The findings from the study demonstrated significance association of adherence and being in these groups. A major reason may be due to the high stigma levels witnessed in this community. When HIV-positive people can discuss and interact together with the rest

of community members this can greatly help and motivate them in their treatment. It is therefore important that the hospital in partnership with other stakeholder's support and sponsor community based organizations that integrate PLWHIV to promote themselves more effectively.

Research:-There is need to explore further the differential behavior of men with regard to there low participation in social networks with a focus to community groups.

REFERENCES

1. Horizons/Population council, International Centre for Reproductive Health and Coast Province General Hospital, Mombasa-Kenya. *Adherence to Antiretroviral Therapy in Adults: A guide for trainers.* Nairobi: Population Council; 2004.

2. National Aids Control Council. *Kenya HIV/AIDS Data Booklet*.Nairobi: NACC; 2006.

3. Williams. A, Friedlan G. Adherence, compliance and HARRT.*AIDS Clinical Care*, 9(7):51-53. 1997.

4. Motashari F et al. Acceptance and adherence with HARRT therapy among HIV infected women in correctional facility. *In: Journal of acquired Immune Deficiency Syndromes and Human Retrovirology*. 18:341-348. 1998.

5. Baum, A. & Nesselhof S. Psychological research and the prevention, etiology, and treatment of AIDS. *American Psychologist*. 43:900-906. 1988.

6. Wood E, Hogg RS, Yip B, et al. Is there baseline CD4 cells count that precludes a survival response to modern antiretroviral therapy. *Preventive Medicine AIDS*. 7(5):711-732. 2003.

7. Mehta, S, Moore R. D, & Graham, N. M. H. (1997). Potential factors affecting adherence with HIV therapy. *In: Journal of Acquired Immunodeficiency Syndrome*, 11:1665-1670. 1997.

8. Ministry of Health. *Annual Bulletin for Health Service access, Utilization and Coverage.* Nyanza; Department of Health Management Information System; 2006.

9. Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO). *Aids epidemic update*. Geneva, Switzerland: World Health Organization (WHO); 2007.

10. National AIDS and STI Control Programme, Ministry of Health, Kenya. *Kenya AIDS Indicator Survey 2007: Preliminary Report.* Nairobi, Kenya. 2008.

11. Israelski. D, Gore-Felton C et al. Socio-demographic characteristics associated with medical appointment adherence among HIV-sero-positive patients seeking treatment in a county outpatient facility. *In: Journal of Preventive Medicine.*; 33: 470-475. 2001.

12. Jordan. J Cahn. P et al. Abacavir compared to protease inhibitors as part of HAART regimens for treatment of HIV infection: patient satisfaction and implications for adherence. *AIDS Patient Care and STDs.* 19 (1): 9-18. 2005.

13. Mannheimer SB, Telzak E et al. Quality of life in HIV-infected individuals receiving antiretroviral therapy is related to adherence. In:*Journal of AIDS Care*. 17:10-22. 2005.

14. Edward J, Jean B. Nachega et al. Adherence to Antiretroviral Therapy in Sub-Saharan Africa and North America: A Meta-analysis. *JAMA.*; 296(6):679-690. 2006.

15. Bardeguez AD et al. Adherence to antiretrovirals among US women during and after pregnancy. In: *Journal of Acquired Immune Deficiency Syndrome.*; 48: 408–417. 2008.

16. N.C Talam, P. Gatongi et al. 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 Heath*. 5 (2): 74-78. 2008.

17. Gonzalez J, Penedo S, *et al*. Social support, positive states of mind, and HIV treatment adherence in men and women living with HIV/AIDS. *Health Psychology*. 23(4): 413-418. 2004.

18. Donlou, J, Wollcott N, et al. Psychosocial aspects of AIDS and AIDS-related complex: A pilot study.1985 In: *Journal of Psychosocial Oncology*. 3:39-55. 1985.

19. Beckham, D. Group work with people who have AIDS. In: *Journal of Psychosocial Oncology*. 6:213-218. 1989.

20. Herek, G.M, Glunt, E.K. An epidemic of stigma: Public reactions to Aids. *American Psychologist*. 43:886-891. 1998.

21. Flaherty J, Richman J. Gender difference in the perception and utilization of social support: Theoretical perspective and an empirical test. *Social Science and Medicine*. 28; 1221-1228. 1989.

22. Rosario, M, Shinn, M et al. Gender differences in coping and social supports: Testing socialization and role constraint theories. In: *Journal of community Psychology*. 16:55-69. *1988*.

23. Troll L.E. Gender differences in cross generation networks. *Sex Roles*. 17:751-766. 1987.

24. Neighbors, H.W, Jackson, J.S. The use of informal and formal help: Four patterns of illness behavior in the black community. In: *American Journal of community Psychology*. 12:629-644. 1984.

25. Kaplan, R.M, Hartwell, S.L. Differential effects of social support and social networks on physiological and social outcomes in men and women with type II diabetes mellitus. *Health Psychology*. 6:387-398. 1987.

26. Broadhead R. S, Heckathorn, D. *et al.* increasing drug user's adherence to HIV treatment: results of a peer-driven intervention feasibility study. *Social Science & Medicine*. 55: 235-246. 2002.

27. Mugenda O.M, Mugenda A.G. *Research Methods: Quantitative and Qualitative Approaches*. Nairobi: Acts Publisher; 1999.

28. Haynes RB, Haines A. Barriers and bridges to evidence-based health care practice. *BMJ*; 317: 273-276. 1998.

29. Besch CL. Adherence in clinical trials. In: *Journal of Acquired Immunodeficiency Syndrome.* 9:1-10. 1995.

30. Orrell C, Word R. Initial data on antiretroviral adherence in cape Town, South Africa. In program and abstracts of the 1st IAS conference on HIV pathogenesis and treatment. 696 Boenes Aires. Abstract. July 2001.

31. Nachega J. B et al. Adherence to antiretroviral therapy in HIV-infected adults in Soweto, South Africa. *AIDS Res Hum Retroviruses.* 20:1053-6. 2004.

APPENDICES

APPENDIX 1: INTERVIEW SCHEDULE

A1. Identification:

A	Serial number	[_ _|_ _][__|__]__]
B	INTERVIEWER'S Name	
C	Date of interview	
D	Start time _____ AM/PM	Stop time _____ AM/PM
E	FIELD CHECKS Interviewer checked questionnaire 1 Supervisor check questionnaire 2	
*	Enter details of incomplete or refused interviews here:	

INFORMED CONSENT
Read the following statement to client :

My name is
……

The Comprehensive Care Centre has been found to be very important in serving the needs of PLWHIV. As a step to improving services offered by the centre we are conducting a study to assess the role of social support system on adherence to antiretroviral treatment.

Our discussion today is estimated to take between one hour to one and half hour. You will be required to sign on this form or emboss your left thumbprint. All information shall be treated in confidence as much as possible; your name will not be recorded in any records which one can use to know what you said.

Your participation in the study is voluntary. There are no risks for refusing to participate, likewise, there are no direct benefits for accepting to participate in the study besides the potential benefit the study has, in improving support offered to clients for improved treatment outcome upon the use of the findings by the hospital and other partners.

The Institutional Research Ethical Committee (IREC) of Moi University/Moi Teaching Referral Hospital has approved this study, which ensures the rights of participants are not violated. Should you have any question with regard to this research or your rights as a study participant you may write to the undersigned?

READING ENDS HERE

Institutional Research Ethical Committee (IREC)
Moi University/Moi Teaching Referral
P.O.B.O.X 4606
Eldoret.
Tel:33471/2/3

At this time, do you want to ask me anything about the study? May I begin the interview now?

Signature of interviewee:
_____Date:_____

RESPONDENT AGREES TO BE INTERVIEWED ..... 1 ↓	RESPONDENT DOES NOT AGREE TO BE INTERVIEWED ..... 2 →END

SECTION 1: DEMOGRAPHIC ATTRIBUTES

#	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP TO
	READ: First, I would like to know some information about you.		
1	Sex (of the interviewee) RECORD OBSERVATION	Male.....…….1 Female ..... ……2	
2	Where do you live?	Within Kisii municipality……...1 Outside Kisii municipality……..2	
3	How old were you at your last birthday? (Record to the nearest whole number)	AGE IN COMPLETED YEAR [ ] [ ] Years	
4	Marital status?	Single ……...1 Married.…….2 Divorced ……..3 Widowed …….4 Separated …….5	
5	Do you live with any family members?	Yes ..... ……1 No .....…….2	□7
6	How many family members do you live with?	[ ] [ ]	
7	Have you ever attended school?	Yes .....……1 No .....…….2	□ 9
8	What is the highest level of school did you attend?	Primary …….1 Vocational…….2 Secondary …….3 Tertiary college ……4 University …….5	
9	What is your occupation i.e. what kind of work do you do to earn a living?	Formal employment ..... 1 Informal employment ..... 2 Unemployment ..... 3 Other_____ 8 (SPECIFY)	

SECTION 2:KNOWLEDGE AND PERCEPTIONS			
10	In your view, do you think ARVs are beneficial to you?	YES.....1 NO 2	
11	In your opinion for how long do you think an individual living with HIV should take ARVs?	One year…….……..…1 2-5 years…….……..…2 Above 10 years……3 For life ……....4 Do not know…….6 Others……...9 (Specify)	
12	In your opinion, who should be started on ARV?	Those who look thin…….……..1 Those with low CD4 count…….2 Those with high viral load.……..3 Those diagnosed with HIV…....4 Do not know……..……..5 Other……9 (Specify)	
13	In the community, are there any fears that individuals have, on the use of ARVs?	Yes ..... ……1 No…….2	□ 15
14	What are some of the perceived fears? (Multiple answers possible)	Drugs might not work…...……..1 He may become sterile…..…..2 Inadequate food…….……...3 Stigma…….……4 Others.....9 (SPECIFY)	
15	Have you seen or heard any messages about ARV adherence?	Yes ..... 1 No 2	□ 19

16	What kind of information have you seen or heard on ARV adherence? (WRITE ANSWER IN THE SPACE PROVIDED)	_____ _____ _____ _____ _____	
17	Where did you see or hear this information? (Multiple answers possible) PROBE ONCE: "Anywhere else?"	RADIO .....A TV .....B POSTER .....D BROCHURE .....E BILLBOARDS……F BARAZA .....G HEALTH CLINIC STAFF.....H CHW .....K Other _____ .....N (specify)	
18 a	Did the information cause you to think differently about the need to comply with the treatment regimen?	YES..... ……1 NO 2	
18 b	What were some of the thoughts?	_____ _____ _____ _____	

SECTION 3: ADHERENCE ATTRIBUTES

#	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP TO
19	How long have you been in the antiretroviral treatment program? (Record to the nearest whole number)	[ ] Years [ ] Months	
20	How often do you visit this facility to replenish the drugs?	After one week……..1 Every two weeks……...2 Every month……..3 Other_____8 (Specify)	
21	How many times do you take your drugs in a day?	[ ] Times	
22	Do you stick to the specific times of the day in taking your drugs?	Yes ..... …….1 No……...…….2	□ 24
23	What are some of the reasons that prevent you from sticking to the timing? (Multiple responses possible)	Forgetting……..1 Being too busy……..…2 Being away from home…….3 Too many drugs…….4 Stigma……5 Other_____8 (Specify)	
24	In the last 24 hrs, have you failed/missed to take your medication according to the prescription?	Yes ....……1 No…….……..2	□ 27
25	How many times have you missed to take medication as prescribed?	[ ] Times	
26	What were some of the reasons that made you miss/fail to take your drugs as prescribed? (Multiple responses possible)	Forgetting……..1 Being too busy……..…2 Being away from home…….3 Too many drugs…….4 Stigma……5 Other_____8	

27	Have you ever missed an appointment with the clinician?	Yes ..... ……1 No .....…….2	□ 29
28	What were some of the reasons that made you miss the appointment with the clinician? (Multiple responses possible)	Forgetting……..1 Being too busy……..…2 Being away from home…….3 Feeling sick…..…….4 Stigma……5 Other_____8 (Specify)	
SECTION 4:SOCIO-SUPPORT ATTRIBUTES			
29	In general when you come to receive your ARV medications who brings you to the hospital? (Multiple responses possible)	Come by Myself ……1 Father…….…….…2 Mother…….……3 Siblings……...4 Husband…….……....5 Wife……....6 Child…….……...7 Friend…….…….9 Neighbour……..10	
30	When you come back for an appointment does the clinician inquire on your progress with the treatment?	Yes..... ……1 No…….2	
31	Do the health workers advise you on how to take the drugs and the effects of not complying with the treatment?	Yes..... ……1 No…….2	
32	How do you feel about the time you waited today before receiving attention from the health workers? (Read all options to the patient)	Definitely too long ……...1 Long……..2 Acceptable……3 Short …….……..4 Does not know ……9	
33	How would you describe your communication with the health workers?	Very good ..... 1 Good ..... 2 Poor ..... 3 Very poor 4	

34	Have you disclosed your status to any of the following?		
	Persons	**Yes**	**No**
	Spouse		
	Father		
	Mother		
	Brother		
	Sister		
	Friends		
35	What are some of the reasons for non disclosure? For those who answered no to all the persons in Q 34. (Multiple answers possible)	Personal decision ..... 1 Fear of others knowing ..... 2 Fear of losing Job. ..... 3 Fear of being accused ..... 4 Other ..... 9 (SPECIFY) ---------- -	
36	Do you belong to any support group in your village/community?	Yes ..... ……1 No……2	□ 41
37	Which of this support groups do you belong or participate in? (Multiple responses possible)	CBOs..... 1 NGOs ..... 2 Churches ..... 3 Women group ..... 4 Men's groups..... 5 Other ..... 9 (SPECIFY)	
38	In your opinion, do you get support from these groups in meeting your ART needs?	Yes…….……1 No ..... ……..2	□ 41
39	What kind of support do you get from these groups? (Multiple responses possible)	Psychological ..... 1 Financial ..... 2 Physical care..... 3 Income generating activities..... 4 Nutritional support..... 5 Legal support..... 6 Other ..... 9 (SPECIFY)	

<table>
<tr><td>40</td><td>In general, how satisfied are you with the overall support (help) you get from being a member of the support group?
(Read all options to the patient)</td><td>Not satisfied 1
Not quite satisfied..... 2
Moderately satisfied..... 3
Very satisfied..... 4</td><td></td></tr>
<tr><td>41</td><td>Do friends or family members help you to remember to take your medications?</td><td>YES..... ……..1
NO ..... ……..2</td><td>□ 43</td></tr>
<tr><td>42</td><td>To what extent do they help you to remember to take your medications?</td><td>Occasionally..... 1
Sometimes..... 2
Always. 3
Other…….9
(Specify)</td><td></td></tr>
<tr><td>43</td><td colspan="2">Do you receive any material/cash support from the following to support your ART needs?
<table><tr><th>Persons</th><th>Yes</th><th>No</th></tr><tr><td>Spouse/partner</td><td></td><td></td></tr><tr><td>Other close family members</td><td></td><td></td></tr><tr><td>Friends/Neighbors</td><td></td><td></td></tr><tr><td>Local community organizations</td><td></td><td></td></tr></table></td><td></td></tr>
<tr><td>44</td><td>In general, how satisfied are you with the overall support (help) you get from your family members?
(Read all options to the patient)</td><td>Not satisfied……...1
Not quite satisfied……..2
Moderately satisfied……...3
Very satisfied..... ……4</td><td></td></tr>
<tr><td>45</td><td>In general, how satisfied are you with the overall support (help) you get from your friends?
(Read all options to the patient)</td><td>Not satisfied……1
Not quite satisfied……...2
Moderately satisfied……3
Very satisfied……..4</td><td></td></tr>
<tr><td colspan="3">THANK RESPONDENT, END INTERVIEW.</td><td></td></tr>
</table>

APPENDIX 2: FOCUS GROUP DISCUSSION GUIDE

INFORMED CONSENT
Read the following statement to the participants:

My name is
……

The Comprehensive Care Centre has been found to be very important in serving the needs of PLWHA. As a step to improving services offered by the centre we are conducting a study to assess the role of social support system on adherence to antiretroviral treatment.

Our discussion today is estimated to take about 1 and a half to 2 hours. You will not be required to sign anywhere instead we are requesting your permission to record our discussion on a tape recorder. We will treat all information in confidence as much as possible. Your name shall not be recorded in the cassette or in any records which can be used to link responses to participants. The final analysis shall focus on what was said in general on different topics and not what was said by individuals. We shall request all participants in the discussion not to tell others what they hear from the discussion.

Your participation in the assessment is voluntary. There are no risks for refusing to participate. You may be uncomfortable with some questions, in that event you are also free not to answer specific questions or end the discussion. Likewise, there are no direct benefits for accepting to participate in the discussion besides refund of travel expenses. The real benefit of this study lies in its potential to improving Patient Support Centre services upon the use of the findings by health care and social workers and other partners in the improvement of PSC services to the patients.

The Institutional Research Ethical Committee (IREC) of Moi University/Moi Teaching Referral Hospital has approved this study, which ensures the rights of participants are not violated. Should you have any question with regard to this research or your rights as a study participant you may write to the undersigned?

READING ENDS HERE

Institutional Research Ethical Committee (IREC)
Moi University/Moi Teaching Referral
P.O.B.O.X 4606
Eldoret.
Tel:33471/2/3

At this time, do you want to ask me anything about the study? May we begin the discussion now?

Climate setting

I. Let's start by introducing ourselves, tell us who you are, what you do, whether you are married or not and how many children you have? Remember let us only use one name.
II. So how do you spend your weekday? What about weekends?
III. And what do you do with your free time?

---

1) What can you say about the situation of HIV and AIDS in your community?
2) What role do you play as a community in addressing the HIV and AIDS situation?
3) What support do you give to people living with HIV and AIDs in this community?
4) How do you relate with the health facility in terms of supporting people living with HIV and AIDs.
5) What do you understand with the term adherence to antiretroviral treatment?
6) Why is adherence to antiretroviral treatment important to people living with HIV and AIDS? **(Probe for perceived benefits).**
7) As a community, do you have any perceived fears about antiretroviral treatment?
8) In you opinion what factors affect adherence to antiretroviral treatment? **Probe for personal, economic, cultural, physical, structural, and systemic factors.**
9) In terms of adherence to antiretroviral treatment, do you relate with the health facility in ensuring compliance with the treatment to PLWHIV?
10) As family members and caregivers what role do you undertake to contribute to adherence to antiretroviral treatment?
11) What challenges do you experience in ensuring people living with HIV and AIDS comply with the treatment?
12) In your view, what can be done to improve adherence to antiretroviral treatment?

Thank you for your cooperation