FACTORS ASSOCIATED WITH THE PREVALENCE OF NON ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG HIV POSITIVE PATIENTS IN KIBRA SLUMS, NAIROBI, KENYA

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Factors associated with the Prevalence of Non Adherence to Antiretroviral Therapy among HIV Positive Patients in Kibra Slums, Nairobi, Kenya.

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A Thesis Submitted in Partial Fulfillment for the Degree of Master of Science in Epidemiology in the Jomo Kenyatta University of Agriculture and Technology

DECLARATION

| This thesis is my original work and has not been prese university. | ented for a degree in any other |
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DEDICATION

I dedicate this thesis to my loving husband Michael, my son Nathan, brother in law Maurice, my sister Stella, my nieces; Rachel and Clare, nephews; Tommy and Ryan also to my friends; Esther, Florence, Miriam, Kilai, Rose, Ruth, Velma, Sarah, and Catherine. I love you all.

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TABLE OF CONTENTS

| DECLARATION | ii |
|---------------------------------|------|
| DEDICATION | iii |
| ACKNOWLEDGEMENT | iv |
| TABLE OF CONTENTS | v |
| LIST OF TABLES | X |
| LIST OF APPENDICES | xiii |
| ABBREVIATIONS AND ACRONYMS | xiv |
| DEFINITION OF OPERATIONAL TERMS | xvi |
| ABSTRACT | |
| ADSTRACT | xvii |
| CHAPTER ONE | |
| | 1 |
| CHAPTER ONE | 1 |
| CHAPTER ONEINTRODUCTION | 11 |
| CHAPTER ONE | 1111 |
| INTRODUCTION | 111 |

| 1.5.1 Main Objective | 6 |
|--------------------------------------|----|
| 1.5.2 Specific Objectives | 6 |
| CHAPTER TWO | 8 |
| LITERATURE REVIEW | 8 |
| CHAPTER THREE | 15 |
| MATERIALS AND METHODS | 15 |
| 3.1 Study Area | 15 |
| 3.2 Research Design | 16 |
| 3.3 Study Population | 16 |
| 3.4 Inclusion and Exclusion Criteria | 16 |
| 3.4.1 Inclusion Criteria | 16 |
| 3.4.2 Exclusion Criteria | 16 |
| 3.5 Sample Size Determination | 16 |
| 3.6 Sampling Technique | 17 |
| 3.7 Study Tools and Data Collection | 17 |
| 3.8 Data Storage and Management | 18 |
| 3.9 Data Analysis and Presentation | 18 |

| 3.10 Ethical Considerations |
|--|
| 3.11 Expected Application of Research Results |
| CHAPTER FOUR20 |
| RESULT20 |
| 4.1 Distribution of the respondents with regard to the level of non-adherence 20 |
| 4.2 Distribution of respondents' response with regard to reasons for non-adherence 21 |
| 4.3 Social-demographic and social- economic characteristics of study participants 21 |
| 4.3.1 Distribution of the respondents by gender |
| 4.3.2 Distribution of the respondents by age |
| 4.3.3 Distribution of respondents by marital status |
| 4.3.4 Distribution of the respondents by level of education and ART adherence 24 |
| 4.3.5 Level of income and ART adherence |
| 4.3.6 Distribution of respondents with regard to the area of residence |
| 4.4 Distribution of respondents with regard to CD4 cell count before ART initiation26 |
| 4.5 Distribution of respondents with regard to their knowledge on ART and how i influences non-adherence |
| 4.5.1 Distribution of respondents with regard to their knowledge that ART prolong |

| 4.5.2 Distribution of respondents' response that only those at the AIDS stage should take ART |
|---|
| 4.5.3 Distribution of respondents' response that ART reduces viral load29 |
| 4.5.4 Distribution of respondents' response that ART cures HIV30 |
| 4.5. 5 Distribution respondents regarding their attitude towards ART30 |
| 4.5.6 Distribution of respondents' response that ART is associated with stigma31 |
| 4.5.7 Distribution of respondents' response that ART will not work without food .31 |
| 4.5.8 Distribution of respondents' response that taking ART is a waste of time32 |
| 4.5.9 Distribution of respondents' response with regard to their practices while on ART |
| 4.5.10 Distribution of respondents' response with regard to the use of traditional/herbal medicine concurrently with ART |
| 4.5.11 Distribution of respondents' response with regard to the sharing of their ART medicine with other HIV infected patients who are not on ART34 |
| 4.5.12 Distribution of respondents' response with regard to taking ART anytime34 |
| 4.5.13 Distribution of respondents' response with regard to missing appointments for ART refill |
| 4.5.14 Distribution of respondents' response with regard to adherence practices35 |
| 4.5.15 Distribution of respondents' response with regard to adherence counseling 36 |

| 4.5.16 Distribution of respondents' response with regard to having something | g to |
|--|------|
| remind them to take their ART medicine | .37 |
| | |
| 4.5.17 Distribution of respondents' response with regard to missing a dosage | |
| ART would interfere with the treatment | 38 |
| 4.5.18 Multivariata Lagistia Dagressian Analysis for knowledge attitudes | and |
| 4.5.18 Multivariate Logistic Regression Analysis for knowledge, attitudes, | |
| practices associated with non adherence (Overall Model) | .38 |
| 4.6 Treatment related information for the study participants | 40 |
| | |
| CHAPTER FIVE | 42 |
| | |
| DISCUSSION AND CONCLUSIONS | 42 |
| 5.1 Discussion | .42 |
| | |
| 5.2 Study limitations | 48 |
| | |
| 5.3 Conclusions | 48 |
| 5.4 Recommendation | .48 |
| | |
| REFERENCES | 50 |
| | |
| APPENDICES | 61 |

LIST OF TABLES

| Table 4.1: Distribution of respondents by ART adherence level |
|---|
| Table 4.2: Distribution of respondents' response with regard to reasons for no- adherence |
| Table 4.3: Adherence levels of respondents by gender 22 |
| Table 4.4: Adherence levels of the respondents by age 23 |
| Table 4.5: Adherence levels of the respondents with regard to their marital status24 |
| Table 4.6: Distribution of the respondents by level of education and adherence level |
| Table 4.7: Distribution of income and adherence level 25 |
| Table 4.8: Adherence levels of the respondents with regard to the area of residence 26 |
| Table 4.9: CD4 cell count at the time of ART initiation and the level of adherence .27 |
| Table 4.10: Distribution of respondents' response with regard to their knowledge about the role of ART in HIV management |
| Table 4.11: Distribution of respondents' response that ART helps to prolong life28 |
| Table 4.12: Distribution of respondents' response that only those with AIDS should take ART. 29 |
| Table 4.13: Distribution of respondents' response with regard to ART reduces viral |

| Table 4.14: Distribution of respondents' response that ART cures HIV30 |
|--|
| Table 4.15: Distribution of respondents regarding their attitude towards ART30 |
| Table 4.16: Distribution of respondents' response that ART is associated with stigma |
| Table 4.17: Distribution of respondents' response that ART will not work without food 31 |
| Table 4.18: Distribution of respondents' response that taking ART is a waste of time |
| Table 4.19: Distribution of respondents' responses with regard to their practices while on ART at Amref-Kibra 33 |
| Table 4.20: Distribution of respondents' response with regard to the use of traditional/herbal medicine instead of ART. 33 |
| Table 4.21: Distribution of respondents' response with regard to sharing ART with other HIV infected patients. 34 |
| Table 4.22: Distribution of respondents's response with regard to taking ART any time |
| Table 4.23: Distribution of respondents' response with regard to missing appointments 35 |
| Table 4.24: Distribution respondents' response with regard to adherence practices .36 |
| Table 4.25: Distribution of respondents' responses with regard to adherence counseling 37 |

| Table 4.26: Distribution of respondents' response with regard to having son | neone to |
|---|-----------|
| remind them to take their ART | 37 |
| Table 4.27: Distribution of respondents' response with regard to missing a company of the company of th | dosage of |
| ART would interfere with the treatment | 38 |
| Table 4.28: Overall multivariate Logistic Regression for knowledge, attitud | es and |
| practices of respondents' responses | 39 |
| Table 4.29: Treatment related information of HIV patients at Amref-Kibra | |
| community-based health centre | 41 |

LIST OF APPENDICES

| Appendix I: Consent form | 61 |
|--|----|
| Appendix II: Questionnaires | 63 |
| Appendix III: Treatment related information of HIV infected patients at Amref-Kibra Community-Based Health centre. | 73 |
| Appendix IV: Research Authorization Permit | 74 |
| Appendix V: Ethical Clearance | 75 |
| Appendix VI: A Map Of Kibra Slums | 77 |

ABBREVIATIONS AND ACRONYMS

AIDS Acquired Immunodeficiency Syndrome

AMREF African Medical and Research Foundation

ARV Antiretroviral

CASE Centre for Adherence Support Evaluation

CD4 Cluster of Differentiation 4

EWI Early Warning Indicator

HAART Highly Active Antiretroviral Therapy

HIV Human Immunodeficiency Virus

HIVDR HIV Drug Resistance

INSTI Intergrase Strand Transfer Inhibitor

MSF Medecins Sans Frontieres

NRTIs Nucleoside Reverse Transcriptase Inhibitors

NNRT Non-Nucleoside Reverse Transcriptase

NACC National AIDS Control Council, Kenya

NASCOP National AIDS and STI Control Program Kenya

PIs Protease Inhibitors

PLWHA People living with HIV and AIDS

SPSS Statistical Package for the Social Sciences

UNAIDS United Nations Acquired Immunodeficiency Syndrome

UNICEF United Nations International Children's Emergency Fund

UN United Nations

W.H.O World Health Organization

DEFINITION OF OPERATIONAL TERMS

Treatment Failure-

Treatment failure is defined by W.H.O. by one of the following criteria: clinical (new or recurrent WHO stage 4 or certain stage 3 conditions); Immunological (CD4 decrease to pre-therapy baseline or below 50% falls from the on-treatment peak value or persistent CD4 levels < 100 cell/mm³); or virological (plasma viral load> 1000 copies/ml after six months of antiretroviral treatment therapy.

Adherence-

Adherence has been defined as taking medications or interventions correctly according to prescription. For the purpose of this study, adherence was determined by use of A CASE adherence questionnaire. CASE is widely used adherence tool developed by the New York Academy of Medicines' for measuring ART adherence. It consists of three adherence questions rated on a Likert scale. A composite score is computed from the responses from the CASE questions. A composite score of 10 and above signify better adherence while a score of less than 10 signify poor ART adherence.

ABSTRACT

The efficiency of highly active antiretroviral therapy (HAART) for the human immunodeficiency virus (HIV) is well established, but its effectiveness depends particularly on the adherence of patients to the drugs. Adherence of 95% or greater to antiretroviral drugs is generally considered necessary to achieve optimal virologic suppression in HIV-infected patients. While Kenya has rolled out ART access programs, data on adherence to ART is limited especially considering that new cases of HIV have continued to increase recently. Understanding factors associated with poor adherence is essential to improve patient compliance, maximize virologic suppression, and reduce morbidity and mortality. The main objective of this study therefore was to determine factors associated with non-adherence among adult HIV patients attending the Amref-Kibra community based health centre in Nairobi, Kenya. Structured questionnaires were administered to 280 study participants. Data on CD4 cell count before ART initiation was obtained from patients' health records. Non-adherence to ART was determined by the CASE adherence tool in which patient's scores were summed up to obtain a composite score that ranged from 3 to 16 points. Patients with Index score≤ 10 points were classified as non-adherent and> 10 adherent. Other data generated from the questionnaire were keyed into SPSS and analyzed for frequencies, cross-tabulations, and chi-square test. Multivariate logistic regression was done to determine the relationship between the independent variables and the dependent variable of the study. Prevalence of non adherence was 18%. Factors that were significantly associated with non adherence include; forgetfulness (19%), side effects (17.5%), pill burden (15.7%), and lack of disclosure (14.6%). Results on CD4 cell count showed that 9.9% of patients with CD4 cell count < 250 exhibited ART non-adherence compared to 8% of the patients with CD4 cell count>250. From multivariate logistic regression analysis the study also showed that inadequate knowledge about the role of ART in HIV management, poor attitudes and practices are associated with non-adherence. In conclusion, factors that were significantly associated with non-adherence in this study were patient related. Forgetfulness was the most common reasons for non-adherence to ART. Therefore, adherence counseling and health information dissemination need to include strategies to minimize forgetfulness using memory aids such as pill boxes and written schedule. Patients should also be informed about the side effects that they are most likely to experience based on the ART regimen they have been put on. A simplified regimen such as two pills once or twice daily should be considered to reduce non-adherence cases associated with pill burden. There is need to develop skill to maintain adherence in the non-disclosure state or design a way to encourage for disclosure. In addition, further studies on adherence rate and its determinants with multiple adherence measurements to resolve the barriers to non-adherence are also recommended. Initiating ART for individuals as soon as they become eligible is important for success of ART program.

CHAPTER ONE

INTRODUCTION

1.1 Background

Acquired Immune Deficiency Syndrome (AIDS) is one of the most destructive epidemics the world has ever witnessed. Presently an estimated 33.4 million people are living with HIV worldwide; nearly two thirds of them live in Sub-Saharan Africa (Chi et al., 2009). Infection with the Human Immunodeficiency Virus (HIV) leads to depletion of the immune system and increases the risk of opportunistic conditions which are responsible for increased mortality (Lewthwaite & Wilkins, 2009). The introduction of highly active antiretroviral combination therapy (HAART) since 1996 has substantially improved the prognosis of HIV-infected patients in industrialized countries (Egger et al., 1997). Antiretroviral therapy (ART) is treatment of people infected with human immunodeficiency virus (HIV) using anti-HIV drugs. The standard treatment consists of a combination of at least three drugs (often called "highly active antiretroviral therapy" or HAART) that suppress HIV replication. Three drugs are used in order to reduce the likelihood of the virus developing resistance. Antiretroviral therapy restores immune function and reduces HIV-related morbidity and mortality (Hogg et al., 1999). In addition, antiretroviral therapy has been shown to delay progression to AIDS, resulting in greater and more sustained virological and immunological response (Mills et al., 2011) and improve survival (WHO, 2010).

Antiretroviral therapy is long term treatment, with a potential of drug toxicity and probable emergency of resistance which results into treatment failure. Only few drugs were available initially, but today over 20 approved antiretroviral drugs from four drug classes are available, including nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors (PIs), and fusion inhibitors. ART non-adherence among HIV- infected patients remains a public

health concern. A meta-analysis of 569 ART studies conducted by DiMatteo (2004) revealed that patients display an average non-adherence rate of 25% globally. Another meta-analysis study divulged a combined non-adherence prevalence of 36% (Mill *et al.*, 2006).

The World Health Organization (WHO) has developed a public-health approach to providing HAART in resource limited settings like is the case in many Sub-Saharan Africa countries. This approach takes the realities of weak health systems into account, including the level of training of health care workers, the high patient burden, limited availability of drugs, and the experience from pilot programs (Gills *et al.*, 2006). The choices of regimens in these programs is determined primarily by cost and ease of administration and can include drugs that are no longer widely used in industrialized countries. Viral load monitoring is not considered essential, and individual drug resistance testing is generally not available. A survey of national guidelines developed by 43 low and middle-income countries showed that the public-health approach to antiretroviral therapy has been widely adopted in these countries (Beck *et al.*, 2006).

An estimated 2 million people living with HIV/AIDS were receiving treatment in low and middle income countries by December 2006, representing 28% of the estimated 7.1 million people in urgent need of treatment at that time (WHO, 2007). Despite the optism surrounding the expansion of antiretroviral therapy services throughout Sub-Saharan Africa, concerns have been raised about how best to monitor patients for treatment response, to asses' durability of the current regimens, and to determine the risk of transmitted and acquired drug resistance (Calmly *et al.*, 2007). According to recent studies, ART regimens require 70-90% adherence in order to be effective (Fried land, & Andrews 2001). However, long term sustainability of adherence to antiretroviral therapy (ART) requires accurate and consistent monitoring, and this is a particular challenge to many countries in Sub-Saharan Africa (Fried land & Andrews, 2001). It is further challenged by various social and clinical obstacles including inadequate suppression of viral replication by ART due to poor adherence to therapy, low potency of the

antiretroviral regimens, viral resistance to antiretroviral medications, and pharmacokinetic interaction (Lucas *et al.*, 1999) causing inadequate drug delivery (Wensing *et al.*, 2008). The transmissibility of antiretroviral resistant viruses from person to person further compounds the problem as a clinical and public health challenge (Truong *et al.*, 2006).

According to Kenya AIDS Indicator Survey (KAIS) 2012 Report, 58% of HIV- infected persons aged 15-64 were eligible for antiretroviral (ART) treatment. 63% were currently on ART and among those on ART, 78% achieved viral suppression. In developed nations, a study assessing ART adherence among HIV positive patients in the United Kingdom reported a composite measure of non-adherence rate of 58%, particularly among TB/HIV co-infected patients (Sherr et al., 2008). A survey done in the USA revealed that nearly 21% of AIDS patients, on ARV drugs, missed a dose in 24 hours while 34% had skipped a dose in 3 days perhaps due to dietary restrictions, stigma and changes in lifestyle associated with antiretroviral therapy (Stone, 2000). In Cuba, a study among 847 HIV patients showed 70.6% self-reported adherence (Aragones et al., 2006) as a result of self-efficacy, changing treatment regimens, good communication with the clinician, commitment to and opinions treatment, improves adherence. This report is consistent with the findings of Mills et al., (2006) that reported ART prevalence of 77% for Africa. From the available data, it is evident that ART non-adherence rates are higher among HIV patients in developed countries (D'Armino et al., 2002). However, adherence rates are slightly higher in developing countries.

In Africa, recent studies have reported non-adherence prevalence of 23% for (Wakibi *et al.*, 2011). However, optimal adherence is particularly difficult for HIV positive individuals because ART regimens are complicated, have complex side effects, and associated stigma, psycho-social, clinical setting and cultural barriers (Peterson *et al.*, 2000).

In Sub-Saharan African countries studies have shown low treatment adherence among HIV positive patients; with 63% adherence rate in South Africa, (Orrell, 2003); 68% in Uganda (Byakika *et al.*, 2005), 54% in Nigeria (Iliyasu *et al.*, 2005). Non-adherence prevalence of 24% (Amberbir *et al.*, 2008) and 13% (Marcellin *et al.*, 2008) were reported in Southwest Ethiopia and Cameroon respectively. Higher adherence in Cameroon were associated with consistent treatment of co-infected patients, counseling, social and economic support. At least 80% adherence is required for virological suppression of HIV and rates below this are associated with poor adherence in patients (Peterson *et al.*, 2000).

ART rates in Kenya remain inconsistent. Different studies have reported varied rates with 64% rates in Mombasa (Munyao *et al.*, 2005); 48% in Kibra, Nairobi (Ellis *et al.*, 2006), and 56.8%in Eldoret (Talam *et al.*, 2008). A recent study by Wakibi *et al.* (2011) revealed a non-adherence rate of 18% among HIV patients in Nairobi.

Non-disclosure of HIV status, alcohol use, illiteracy, side effects, stigma, and distance to hospital has been documented as the major barriers to optimal adherence (Mariana *et al.*, 2008; Serna *et al.*, 2008). Similarly, lack of knowledge, and negative perception towards HIV and ART have significantly affected treatment adherence Chesney, 2003) among HIV positive patients.

1.2 Statement of the problem

ART non-adherence among HIV- infected patients remains a public health concern. Poor adherence to ART is an important concern relating to HIV management. The minimal level of adherence required for antiretroviral drugs to work effectively is 95%. No or partial adherence is associated with detectable viral loads, declining CD4 cell count, disease progression, episodes of opportunistic infections, poor health outcomes in addition to the development of drug-resistant strains of the virus. Proper patient adherence to antiretroviral therapy is crucial in achieving optimal treatment outcome.

Drug-resistant strains of HIV selected through the ongoing replication in the presence of antiretroviral therapy can be transmitted to uninfected or drug-naïve patients leaving them with fewer treatment options (Weinberg *et al.*, 1998).

1.3 Justification of the study

It is hoped that knowledge gained from this study on factors associated with non-adherence among HIV positive patients would help in making recommendations regarding the development of appropriate health education strategies to inform patients on the importance of adherence to ART. Further, outcomes of this study would be used in developing guidelines and education materials that could be used to educate HIV positive patients on ART adherence before ART initiation. Adherence to ART is closely tied to virological, immunological, and clinical outcomes. Small increases in adherence can result in significant improvements in these outcomes. Besides monitoring HIV patients on antiretroviral therapy for treatment failure by use of viral load, it is important also to identify factors that are associated with non adherence which is the second strongest predictor of progression to AIDS and death, after CD4 cell count (Banqsberg et al., 2001).

Documented factors associated with non adherence include, but are not limited to: socio demographic factors for example (age, gender, race, income, education, literacy, housing status, and psychological factors such as mental health, substance use, social climate and support, knowledge and attitudes about HIV and its treatment), treatment regimen for example (number of pills prescribed, the complexity of the regimen, (dosing frequency and food instructions), disease characteristics (the stage and duration of HIV infection, associated opportunistic infections and HIV-related symptoms. The outcomes of this study will help to inform formulation of policies that will reduce cases of antiretroviral treatment failure among HIV/AIDS patients in resource limited settings.

1.4 Research Questions

- 1. What is the prevalence of non-adherence to ART among HIV positive patients?
- 2. How do socio-demographic and socio-economic factors influence antiretroviral treatment non-adherence among HIV positive patients?
- 3. How does the level of CD4 cell count at the time of ART initiation influence non-adherence?
- 4. How do knowledge, attitudes and practices influence antiretroviral non-adherence among HIV positive patients?

1.5 Study Objectives

1.5.1 Main Objective

The purpose of this study was to determine factors associated with non adherence to ART among HIV patients on antiretroviral therapy

1.5.2 Specific Objectives

- 1. To determine the prevalence of non adherence to ART among HIV positive patients attending Amref-Kibra community based health centre.
- To determine how socio-demographic and socio-economic factors influence nonadherence to ART among HIV positive patients attending the Amref-Kibra community based health centre.
- To determine how the level of CD4 cell count at the time of ART initiation influences non-adherence among HIV positive patients attending Amref-Kibra community based health centre.

4. To determine how knowledge, attitudes and practices influence antiretroviral treatment non-adherence among HIV positive patients attending the Amref-Kibra community based health centre.

CHAPTER TWO

LITERATURE REVIEW

Non-adherence to ART may take various forms, such as not taking the medication at all, taking medication at the wrong time, taking the wrong dose due to misunderstanding treatment directions, or prematurely terminating the medication without consulting the health provider (Miller, 1997). Other patterns of behavior indicative of non-adherence include not filling prescriptions, self-adjusting the regimen to modulate side effects and toxicities, and incorrectly understanding the doctor's instructions (Chesney, 2003).

Measurement of ART adherence is often problematic as patients may overestimate their adherence due to recall bias, the demand characteristics of the patient-provider consultation, and the desire to avoid criticism (Gao & Nau, 2000). The most common method used to measure adherence are pill counts, pharmacy refill records, drug level monitoring, and various self-reported instruments (Gill *et al.*, 2005). Several studies have shown a mismatch between self-reported adherence and biomedical markers. In a sample of South Africans only 75% of patients who reported 100% adherence achieved an undetectable viral load, that is <50 copies/ml (Brown, Macintyre &Trujillo, 2003). Assuming a high negative correlation between reported adherence and viral load, this mismatch suggests that patients were unable to accurately report adherence levels.

Three types of factors have been identified as barriers to optimal ART adherence, namely, regimen characteristics, patient characteristics, and the relationship between the provider and patient (WHO, 2008). Regimen characteristics include dosage, the requirement of ingestion with specific foods, toxicity, and side effects.

Since 1996, an overwhelming amount of evidence from clinical trials has been published validating the use of HAART for the treatment of human immunodeficiency virus (HIV) infection. Suppression of HIV replication, immune reconstitution, a halt in disease

progression, increased survival; reduced morbidity and a better quality of life have been defined as the biological and clinical goals of treatment. In countries where access to this standard of care is available, AIDS related mortality and morbidity have significantly declined.

To achieve success near perfect ART adherence to combination regimens is required. Failure to suppress viral replication completely inevitably leads to the selection of drug resistant variants limiting the effectiveness of therapy (Friedland, and Andrews, 2001). Non-adherence in patients on antiretroviral HIV therapy is the strongest predictor of failure to achieve viral suppression below the level of detection and faulty adherence to anti-HIV drugs most often underlies treatment failure. It would appear that >95% adherence may be necessary to adequately suppress viral replication, produce a durable response and halt disease progression (Paterson *et al.*, 2000). This means that missing more than one dose of a regimen per week may be enough to cause treatment failure.

Drug intolerability has been cited as the main reason as to why patients either modify or discontinue regimen (Vo *et al.*, 2008). While this may be a global concern the situation in affluent countries is bearable owing to the treatment options available (Hammer *et al.*, 2008).

Adherence to antiretroviral therapy has emerged as both the major determinant and the Achilles' heel of this success. Antiretroviral adherence is the second strongest predictor of progression to AIDS and death, after CD4 count (Garcia *et al.*, 2002). Incomplete adherence to antiretroviral therapy however is common in all groups of treated individuals. The average rate of adherence to antiretroviral therapy is approximately 70%, despite the fact that long-term viral suppression requires near-perfect adherence (Banqsberg *et al.*, 2001a). The resulting virological failure diminishes the potential for long term clinical success. Drug-resistant strains of HIV selected through the ongoing replication in the presence of antiretroviral therapy also can be transmitted to uninfected or drug-naïve patients leaving them with fewer treatment options (Wainberg *et al.*,

1998). Non-adherence may eventually undermine the dramatic improvement in HIV-related parameters seen in resource-rich countries and expected in developing countries as antiretroviral therapy becomes more widely available.

Adherence is not the only determinant of antiretroviral therapy failure or success. Other factors include genetic differences in drug metabolism, severe baseline immune suppression, prior drug resistance, and concurrent opportunistic infections. Adherence to antiretroviral therapy however, is one of the few potentially alterable factors determining outcomes for patient with HIV. Nonetheless, it is well known that health care providers, in general are unskilled at assessing and improving medication adherence (Banqsberg *et al.*, 2001b). The final crucial step toward ameliorating the impact of HIV- the actual taking of the medication- is often neglected.

A multitude of variables have shown to affect adherence to HAART, some more than others. Almost people living with HIV and AIDS who are currently using anti-HIV drugs are on a regimen of 3 or more drugs (Grierson *et al.*, 2000). The likelihood of a patient's adherence to a given regimen declines with polypharmacy, the frequency of dosing, the frequency and severity of side effects, and the complexity of the regimen (Williams &Friedland, 1997). Drug hypersensitivity is far more common in patients with HIV and regimen associated toxicity is a common predictor of; reason for non-adherence.

Side effects associated with each individual antiretroviral drug are well described and whilst not universal for every patient can be predicted. Usually they defect after the first few weeks of therapy but for some, they persist. Anticipation and fear of side effects also impacts upon adherence (Wikibi *et al.*, 2011). Poor adherence has been associated with patient's desire to avoid embarrassing side effects in certain situations, for example, whilst on a date or attending a job interview (Burgos *et al.*, 1998).

Dietary conditions add to the complexity and often require adjustments in lifestyle. Patients can find their meal schedule compromised by anti-HIV drugs that require dosing on a fasted stomach. This can be particularly difficult if work mates, family or friends are unaware of the patient's HIV status (Grierson *et al.*, 2000). Complicated regimens with rigid dosing intervals may also interrupt sleep. The physical aspects of a particular medication (taste, size, formulation and small) may also impact on patient's ability to be adherent.

Poverty related barriers such as food insecurity, substance abuse, transport and migration affects the patient's access and adherence to ART treatment (Coetzee *et al.*, 2011). In Nairobi for example, poor nutrition, long distances to ART dispensing facilities and forgetfulness due to busy work schedule have been established as the major predictors of non-adherence (Wikibi *et al.*, 2011). Patients living in poverty experience difficulties associated with clinic attendance which is endemic and systematically embedded, to the extent that systemic changes are required to yield better patient outcomes

In a cross-sectional study of HIV clinic patients in Soweto, South Africa, 65% indicated that missing ART doses might lead to deterioration in health, 49% stated that they believed ART could 'cure' HIV (Nachega *et al.*, 2005). The belief the ART could cure HIV was associated with low level of education closely tied with ART adherence (Weiss *et al.*, 2003). Weiss *et al.* (2003) recommend that health providers include questions focused on knowledge of HIV in their assessment of medication readiness and the need for adherence support.

Economic, political, and social realities play an important role in determining the kinds of services that patients receive, the economic strains they experience, and their vulnerability to dropping out of treatment (Coetzee *et al.*, 2011). According to Coetzee and team, only two health care services exist in South Africa; one private and well resourced, and the other public and comparatively poorly resourced, which is a

reflection of the economic realities that characterize South African society and indeed many African countries.

In an effort to improve the quality of life among HIV-infected people, multiple strategies including treatment of patients with Antiretroviral Therapy have been implemented worldwide. Antiretroviral medications for HIV/AIDS are among the most efficacious and the most life transforming of therapeutic innovations of recent years. Antiretroviral Therapy (ART) changes a uniformly fatal disease to a manageable chronic illness with proper use and good adherence level. Antiretroviral Therapy requires near perfect adherence rates (as high as 95% (Sarna et al., 2005). Failure to observe this adherence threshold leads to treatment failure, higher mortality rate, lower rate of increasing CD4 cell count and detectable viral load, lower therapeutic success, disease progression and emergence of drug resistant HIV/ADS strains, and increase in hospital days (Garcia et al., 2003). Unfortunately, maintaining adequate levels of adherence to antiretroviral medications has proved challenging not only for persons living with HIV, but also for healthcare providers because a failing regime as a result of poor adherence will lead to increased opportunistic infections, increased hospitalization, and outpatient visits and thus increased work load (Peterson et al., 2000).

Suboptimal adherence with resultant treatment failure is still common. (Mannheim *et al.*, 2005). Inadequate adherence to treatment is associated with detectable viral loads, declining CD4 counts, disease progression, episodes of opportunistic infections, and poorer health outcomes. Adherence to medication is a dynamic behavior affected by factors related to treatment regimen complexity, patient-related variables, patient-healthcare provider relationships, and the quality of healthcare services (Spire *et al.*, 2002). Patient ART treatment failure is influenced by regimen-related factors such as pill burden, frequency of dosing, adverse drug reactions (ADRs) and fluid, and dietary restrictions (Ingersoll & Cohen, 2008).

Similarly, patient-related factors such as lack of transport, shortage of food, use of traditional medicine, alcohol abuse, depression, stigma and discrimination, and lack of social support undermine adherence (Merten *et al.*, 2010). Further, a poor patient-healthcare provider relationship and low quality services, such as lack of confidentiality and privacy and drug stock-outs, can hamper adherence with ART (Wosti *et al.*, 2012), despite the fact that assessing the level of ART treatment failure and determinant factors is crucial for further improvement of ART adherence. The issues of adherence to antiretroviral therapy are multidimensional.

The potential of ART for long term effectiveness is dependent upon the maximum and durable suppression of viral replication. To accomplish this suppression, patient must practice near-perfect adherence to a complex regimen that often include three or more drugs (Webster & Barr, 1999). Since 1996, an overwhelming amount of scientific evidence has been published that demonstrates the effectiveness of combination therapies for people living with HIV and AIDS. Substantial rates of decline in the number of opportunistic infections and in the prevalence of AIDS related mortality have been observed (Idoko *et al.*, 2006). Antiretroviral drugs must be taken as a lifelong therapy and their success relies on continual adherence to the medication regimen. A rate of approximately 90% is required to avoid rapid development of drug resistance and treatment failure (Monjok *et al.*, 2010).

Systematic reviews have indicated that the most important and frequent factors that negatively impact on adherence in developing countries are cost, stigma, alcohol abuse and structural barriers such as lack of transport and pharmacy stock outs (Monjok *et al.*, 2010). An analysis of the barriers that affect adherence should be reviewed as a dynamic interaction of biological and social factors (Olowookere *et al.*, 2008). Some of the biological variables needed to understand non- adherence can be defined within eight categories: Social economic factors, healthcare system factors, social capital cultural methods of health and disease, personal characteristics, psychological factors, clinical factors and antiretroviral regimen.

Extensive research has been undertaken to understand the underlying factors associated with non-adherence (Sahay *et al.*, 2011). Few studies have also examined the effect of CD4 cell count on survival status of individuals who were on ART (Bachani *et al.*, 2010). Empirical research suggests that non-adherence can lead to virological, immunological, and clinical failure and increase the risk of transmission of drug resistant virus (Abaasa *et al.*, 2008). Further, lower to ART and higher mortality has been observed among individuals with CD4 cell count<200 cells/cmm at the time of ART initiation than those who had a high cell count indicating CD4 cell count being associated with increased mortality corroborating findings from other research studies (Chan *et al.*, 2002).

Knowledge about HIV/AIDS has been identified as a powerful tool to prevent the transmission of this disease. Unfortunately, this knowledge about the disease has not resulted in appreciable changes in attitudes or in behavior modifications in the population (Ogbuji, 2005). For example, a study conducted in 2005 by the University of Ibadan in south-western Nigeria, reported that over 90% of students possessed a good knowledge about HIV/AIDS and its transmission but that only 16% of sexually active students used protection during sexual intercourse. Previous studies have shown that the level of knowledge about transmission of HIV affects attitudes about HIV transmission (Almeida & Vieiva, 2009).

CHAPTER THREE

MATERIALS AND METHODS

3.1 Study Area

The study was conducted at the Amref-Kibra Community-Based Health Centre (AKCBHC) situated at Laini Saba. This is due to the large number of slum dwellers seeking medical services at the facility. In addition, Amref-Kibra offers free voluntary counseling and testing (VCT) for HIV. Those testing positive for HIV are enrolled into the HIV care and treatment program within the facility. Kibra is situated in the western part of Nairobi County hosting one of the largest low social economic and informal settlements (slums) in the continent. Kibra population has been estimated to be between 400,000 and 700,000 with a surface area of 2.38km² hence a population density of 300,000 people per square kilometer. (UN- HABITAT/Research International report (2005). The impact of this high population density on overall resource utilization cannot be overemphasized.

Kibra sub-county hosts a number of villages including; Laini Saba, Lindi, Mashimoni, Siranga, Soweto, Makina, Kianda and Gatwekera. The residents hail from most of the communities in Kenya and include some members of the Nubian community who were originally settled in Makina about half a century ago in the then Kibra. The dominant religions are Christianity and Islam with the former consisting of numerous sects. Social organization - settlement along ethnic groupings and high levels of insecurity with community based neighborhood security as a common coping strategy. In Kibra, there are no government clinics or hospitals. The providers are charitable organizations such as: AMREF, MSF, churches plus some others.

3.2 Research Design

This was a descriptive cross-sectional study design that utilized quantitative method of data collection.

3.3 Study Population

Population consisted of HIV positive patients attending the Amref- Kibra community-based health centre.

3.4 Inclusion and Exclusion Criteria

3.4.1 Inclusion Criteria

Adult HIV positive patients (≥ 18 years of age) who have been on antiretroviral treatment therapy for six months and above, and gave their written/ thumb consent to participate in the study

3.4.2 Exclusion Criteria

HIV positive patients who have not been on antiretroviral therapy for six months and those who declined to give their written/ thumb print consent to participate in the study

3.5 Sample Size Determination

A sample size of 280 was determined using Cochran (1963) formula which is $n=z^2pq/d^2$ using P=24% which is the proportion of HIV patients on ART not reaching optimal levels of adherence, Amberbir *et al.*, (2008).

$$n = \frac{Z^2 P (1-P)}{d^2}$$

Where:

Z = 1.96 standard deviation (SD) at 95% confidence interval (CI)

d = (0.05) precision desired by the study 5%

P = proportion of HIV patients not reaching optimal levels of adherence which should be >95%

Substituting the values; Z=3.8416, P=0.24, (1-p) = 0.76, $d^2=0.0025$

$$(1.96^2)$$
 (0.24) $(1-0.24)$ / 0.0025 = (3.8416) (0.076) / 0.0025 =280

Hence; n= 280 HIV infected Patients who have been on ART for at least six months and above

3.6 Sampling Technique

Study participants were HIV positive patients attending the Amref-Kibra community-based Health Centre HIV care and treatment program. From the facility health records a total of 2850 patients were active on ART hence this was used to form the sampling frame. Systematic random sampling method was used to select every 10th patient who met the inclusion criteria. The interval was calculated by taking the number of adult patients on ART by end of August 2014 which was six months prior to this study which was 2805. This was then divided by the sample size to get 10 (2805/280=10). This process continued on every clinic day until the sample size of 280 was reached.

3.7 Study Tools and Data Collection

A structured questionnaire (refer to appendix II) was designed according to the objectives of the study. The questionnaire comprised of four sections, each having questions on each of the four objectives. The third section contained CASE adherence

questions. Likert types of questions were included whereby respondents indicated the degree to which the study variables influenced their HIV treatment adherence on a four point Likert scale.

Three questions were borrowed from CASE adherence tool to measure ART adherence. CASE is a widely used adherence tool developed by the New York Academy of Medicine's (Mannheimer *et al.*, 2006) for measuring ART adherence. It consists of three adherence questions rated on a likert scale. A composite score is computed from responses to CASE questions. A composite score of 10 and above signifies better adherence while a score of less than 10 signifies poor adherence. Data on CD4 cell count before ART initiation for the study participants was obtained from their health records.

3.8 Data Storage and Management

Data obtained from the study was entered into MS Excel database, coded and secured by a password to ensure confidentiality.

3.9 Data Analysis and Presentation

Patient's score in the CASE adherence tool were summed up to obtain a composite score that ranged from 3 to 16 (Mannheimer *et al.*, 2006). Other generated data from the questionnaire were keyed into SPSS version 20 and analyzed for frequencies, cross tabulations, chi-square test, and multivariate logistic regression to determine relationship between the independent variables and the dependent variable of the study. A p-value <0.05 was considered significant in all statistical analysis.

3.10 Ethical Considerations

Prior to the commencement of the study, ethical approval was obtained from Kenyatta National Hospital/ University of Nairobi-Ethical Review Committee (KNH/UON-ERC. The role of Ethical Review Committee was to ascertain that the code of conduct on

research involving human subjects was adhered to and that a written consent was obtained from study participants. In addition, official permission was sought after from the project manager in charge of Amref-Kibra ART care and treatment project from where data was to be collected.

Data, including questionnaire and files of study participants were kept in cabinets under lock and key. Data obtained from study participants were labeled only with a study code. Their identities were kept confidential and their names were never used in any report, publications or presentations.

3.11 Expected Application of Research Results

It is hoped that knowledge gained from this study on factors associated with non-adherence among HIV positive patients would help in making recommendations regarding the development of appropriate health education strategies to inform patients on the importance of adherence to ART. In addition, the recommendations from the study would provide scholars with avenues for further studies.

CHAPTER FOUR

RESULT

4.1 Distribution of the respondents with regard to the level of non-adherence

Fifty (18%) respondents were non-adherent based on CASE adherence method, while 230 (82%) reported good adherence. CASE adherence tool consists of three adherence questions rated on a Likert scale. A composite score was computed from the responses to the CASE questions. A composite of 10 and above signify better adherence while a score of less than 10 signify poor adherence. Nonetheless, to attain successful treatment outcomes, ART adherence requires more than 95% adherence level. Table 4.1 represents the frequencies of adherence among the respondents.

Table 4.1: Distribution of respondents by ART adherence level

| | Frequency | Percent |
|----------------|-----------|---------|
| Good adherence | 230 | 82 |
| Poor adherence | 50 | 18 |
| Total | 280 | 100 |

From the table 4.1, 230 (82%) respondents good adherence while 50 (18%) reported poor adherence. The prevalence of non-adherence found in this study (18%) is comparable to the continental prevalence (23%) for Africa (Mills *et al.*, 2006).

4.2 Distribution of respondents' response with regard to reasons for non-adherence

Study participants' response with regard to the reasons for non-adherence showed that 19% was due to forgetfulness, side effects (17.5 %), pill burden (15.7%), lack of disclosure (14.6%), depression (12.5%), simply forgot (8.2%), lack of support (7.5%) and lastly due to proximity to the clinic (50%).

Table 4.2: Distribution of respondents' response with regard to reasons for noadherence

| Reason for non-adherence | n | % | 95% CI |
|--------------------------|-----|------|--------------|
| Forgot | 53 | 19 | 14.02-14.51 |
| Side effects | 49 | 17.5 | 13.2-22.5 |
| Pill burden | 44 | 15.7 | 11.65-20.51 |
| Lack of disclosure | 41 | 14.6 | 10.70-19.33 |
| Depression | 35 | 12.5 | 8.86-16.95 |
| Stigma | 23 | 8.2 | 5.27-12.07 |
| Lack of support | 21 | 7.5 | 4.70-11.23 |
| Proximity to the clinic | 14 | 05 | 2.76-8.24 |
| Total | 280 | 100 | 71.16-125.34 |

4.3 Social-demographic and social- economic characteristics of study participants

Study showed that out of 280 participants, 171 (61.1%; 95% CI: 55.1-66.8) were female while 109 (38.9%; 95% CI: 33.1-44.9) were male.

4.3.1 Distribution of the respondents by gender

The study considered the gender of the respondents as a socio-demographic factor that influences ART adherence. Respondents were asked to state their gender and the results were given in table 4.3.

Table 4.3: Adherence levels of respondents by gender

| | Good adherence | Poor adherence | Total |
|--------|----------------|----------------|-----------|
| Male | 90 32% | 19 6.9% | 109 38.9% |
| Female | 140 50% | 30 10.8% | 171 61.1% |
| | 230 82% | 50 18% | 280 100 |

Large proportion of the respondents, 61.15% (171) was female while 38.9% (109) were males. This indicated that there were more females than males in the population. A cross tabulation between gender and adherence level showered that 30 (10.8%) women exhibited poor treatment adherence compared to 19 (6.9%) men.

4.3.2 Distribution of the respondents by age

The study sought to establish age distribution of the respondents who were interviewed in order to determine adherence levels among various age groups and to inform future studies and interventions of the most vulnerable age group. The age groups are summarized in table 4.4 below.

Table 4.4: Adherence levels of the respondents by age

| Years | Good | adherence | Poor | adherence | Total |
|-------|------|-----------|------|-----------|-----------|
| <20 | 0 | 0% | 0 | 0% | 0 0% |
| 20-29 | 37 | 13.2% | 24 | 8.6% | 61 21.8% |
| 30-39 | 31 | 11.1% | 13 | 4.6% | 44 15.7% |
| 40-49 | 108 | 38.9% | 8 | 2.9% | 116 41.8% |
| 50-59 | 48 | 17.1% | 2 | 0.7% | 50 17.8% |
| 60-69 | 6 | 2.1% | 3 | 1.1% | 9 3.2% |
| | 230 | 82% | 50 | 18% | 280 100% |

Majority of the respondents 41.8% (116) were aged between 40-49 years, followed by 21.8% (61) aged 20-29 years and 15.7% (44) were between 30-39 years old. From the results, the bracket 40-49 formed the bulk of the patients in this population. From the table age brackets of 20-24 and 30-39 were at the highest risk of non-adherence. This finding is consistent with the findings of IIiyasu *et al.*, 2005) that found out that younger respondents below the mean age of (39.7 years) were more likely not to adhere to ART.

4.3.3 Distribution of respondents by marital status

Majority of the respondents 79% (221) were married followed by 47 (16.8%) singles and finally 4.3% (12) were divorced. The level of poor adherence (13.6%) was observed highest amongst married couple. This could have been brought about by issues of disclosure of one's status to their spouses thus leading to poor ART adherence. When there is no self- disclosure, the persons may fear to take their treatments when the spouse is present. In such case there is need to develop skill to maintain adherence in the non-disclosure state or design a way to encourage for disclosure.

Table 4.5: Adherence levels of the respondents with regard to their marital status

| Marital status | Good adherence | Poor adherence | Total |
|----------------|----------------|----------------|----------|
| Married | 183 65.4% | 38 13.6% | 221 79% |
| Singles | 37 13.2% | 10 3.6% | 47 16.8% |
| Divorced | 10 3.6% | 2 0.7% | 12 4.3% |
| Total | 230 82% | 50 18% | 280 100% |

4.3.4 Distribution of the respondents by level of education and ART adherence

The study found it important to analyze the level of education of the respondents and their adherence levels. This was important because the level of education determines the ability to understand treatment prescriptions. Respondents' education level were compared to their adherence levels and the results summarized in table 4.6

Table 4.6: Distribution of the respondents by level of education and adherence level

| | Good | adherence | Poor | adherence | Tota | al |
|-------------------------|------|-----------|------|-----------|------|-------|
| Primary | 80 | 28.6% | 17 | 6.1% | 97 | 34.7% |
| Post primary/vocational | 48 | 17.1% | 11 | 3.9% | 59 | 21.0% |
| Secondary | 69 | 24.6% | 8 | 2.9% | 77 | 27.5% |
| Post-secondary | 27 | 9.6% | 8 | 2.9% | 35 | 12.5% |
| No formal education | 06 | 2.1% | 06 | 2.1% | 12 | 4.2% |
| Total | 230 | 82% | 50 | 18% | 280 | 100% |

About 34.7% of the respondents had attained primary level of education approximately 27.5% had secondary school and 12.5% held post-secondary school as the highest level

of education. From the table above, the results showed that 6.1% of primary school level of education exhibited poor adherence compared to 2.1% of those with no formal education. Hence there were no association between level of education and non-adherence. This finding contradicted that of Catz *et al.*, (1999) which found that lower level of education and illiteracy had negative impact on patients' adherence to medication.

4.3.5 Level of income and ART adherence

To determine the level of income, respondents were asked to indicate their average monthly income. Analysis in table 4.6, revealed that majority of the respondents 138 (49.4%) earned less than Kshs. 5000 a month. A bout 31.5% (88) of the respondents earned between Kshs.50001-10,000 a month while 35 (12.5%) earned between Kshs 10001-15,000. However, 6.8% of the respondents considered themselves unemployed thereby could not estimate their monthly income. The results revealed that the amount of income of an individual is somehow proportional to their level of education.

Table 4.7: Distribution of income and adherence level

| Income (Kshs) | Good | adherence | Poor | adherence | Total |
|---------------|------|-----------|------|-----------|-----------|
| <5000 | 115 | 41.2% | 23 | 8.2% | 138 49.4% |
| 5001-10,000 | 78 | 27.9% | 10 | 3.6% | 88 31.5% |
| 10001-15000 | 29 | 10.4% | 6 | 2.1% | 35 12.5% |
| Unknown | 8 | 2.9% | 11 | 3.9% | 19 6.8% |
| Total | 230 | 82% | 50 | 18% | 280 100% |

4.3.6 Distribution of respondents with regard to the area of residence

Majority 16.1% (45) of the respondents residing within Kibra exhibited poor level of adherence compared to 1.8% (5) who was non residents of Kibra. Residents who accessed therapy in clinics within a walking distance from their homes were about two and a half times more likely not to adhere than patients who refilled in far way clinics. These findings together with social stigma associated with ART use suggested that most respondents who accessed free therapy in clinics within walking distance to their homes did so due to lack of choice; speculatively could not afford transport cost to alternative ART clinics.

Table 4.8: Adherence levels of the respondents with regard to the area of residence

| Residing within Kibra | Good | adherence | Poor | adherence | Tota | ıl |
|-----------------------|------|-----------|------|-----------|------|-------|
| Yes | 184 | 65.7% | 45 | 16.1% | 229 | 81.8% |
| No | 46 | 16.4% | 5 | 1.8% | 51 | 18.2% |
| Total | 230 | 82% | 50 | 18% | 280 | 100% |

4.4 Distribution of respondents with regard to CD4 cell count before ART initiation

Result indicated that out of 280 respondents majority had CD4 cell count of 201-250 for (24.5%; 95% C.I:19.6-30.0) and more than six months on ART, followed by 151-200 for (23. %; 95% C.I:18.2-28.4) of the respondents, 101-150 for (12.8%; 95% C.I: 9.1-17.3), 301-350 for (12.5%; C.I:4.0-37.5) of the respondents, 251-300 for (11.3%; 95% C.I:7.8-15.6), 51-100 for (6.0%; 95% C.I: 3.5-9.5) 351-400 for (4.1%;95% C.I:2.1-7.2)of the respondents, 0-50 for (3.0%; 95% C.I:1.3-9.5) of the respondents and lastly above 400 for (2.8%;95% C.I:1.2-5.5) of the respondents. Lower adherence to ART and higher mortality has been observed among individuals with CD4 cell count at the time of ART initiation. 9.9% (28) patients who had CD4 cell count <250 had experienced poor ART

adherence as compared to 22 (8%) of patients with CD4 cell count of >251. This indicates that the baseline CD4 cell count can influence the effect of adherence on survival of HIV infected individuals.

Table 4.9: CD4 cell count at the time of ART initiation and the level of adherence

| CD4 cell count | Good a | dherence | Poor a | dherence | Te | otal |
|----------------|--------|----------|--------|----------|-----|-------|
| <250 | 127 | 45.4% | 28 | 9.9% | 155 | 55% |
| >251 | 102.7 | 36.4% | 22 | 8% | 125 | 44.6% |
| Total | 230 | 82% | 50 | 18% | 280 | 100% |

4.5 Distribution of respondents with regard to their knowledge on ART and how it influences non-adherence

Majority of the respondents agreed that ART helps to prolong life (91%), some respondents agreed that only at the AIDS stage should take ART (30%), ART reduces viral load (91%) while 93% of the patients agreed that ART consists of drugs to cure HIV.

Table 4.10: Distribution of respondents' response with regard to their knowledge about the role of ART in HIV management

| Response | Strongly | Agree | Disagree | Strongly |
|--|----------|----------|----------|----------|
| | Agree | n (%) | n (%) | Disagree |
| | n (%) | | | n (%) |
| ART helps to prolong Life | 202 (72) | 53 (19) | 17 (6) | 8 (3) |
| Only those at the AIDS stage should take ART | 22 (8) | 8 (22) | 87 (31) | 148 (53) |
| ART reduces the viral load | 123 (44) | 132 (47) | 17 (6) | 8 (3) |
| ART consists of drugs to cure HIV/AIDs | 162 (58) | 98 (35) | 8 (3) | 12 (4) |

4.5.1 Distribution of respondents with regard to their knowledge that ART prolongs life

Results of the respondents who agreed to the statement that ART prolongs life were statistically significant ($\chi^2 = 1.252$, p=0.0094).

Table 4.11: Distribution of respondents' response that ART helps to prolong life

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 28 (56%) | 104 (45%) | 1.050 | 0.0004 |
| Disagree | 22 (44%) | 126 (55%) | 1.252 | 0.0094 |

4.5.2 Distribution of respondents' response that only those at the AIDS stage should take ART

Results of the respondents indicated that the proportion of patients who agreed to the statement that only those with AIDS should take ART were not statistically significant ($\chi^2=2.355$, p=0.798)

Table 4.12: Distribution of respondents' response that only those with AIDS should take ART

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 15 (30%) | 96 (42%) | 2.255 | 0.700 |
| Disagree | 35 (70%) | 134 (58%) | 2.355 | 0.798 |

4.5.3 Distribution of respondents' response that ART reduces viral load

Results of the respondents who disagreed to the statement that ART reduces viral load were not statistically significant ($\chi^2 = 1.361$, p= 0.929)

Table 4.13: Distribution of respondents' response with regard to ART reduces viral load

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 20 (40%) | 112 (49%) | 1 261 | 0.020 |
| Disagree | 30 (60%) | 118 (51%) | 1.361 | 0.929 |

4.5.4 Distribution of respondents' response that ART cures HIV

Results of the respondents who agreed to the statement that ART cures HIV were significant ($\chi^2=12.897$, p=0.075)

Table 4.14: Distribution of respondents' response that ART cures HIV

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 25 (50%) | 133 (58%) | | |
| Disagree | 25 (50%) | 97 (42%) | 12.897 | 0.075 |

4.5. 5 Distribution respondents regarding their attitude towards ART

A majority (80%) agreed that ART is associated with stigma, 55% agreed that ART without food will not work, while 6% agreed that taking ART was a waste of time.

Table 4.15: Distribution of respondents regarding their attitude towards ART

| Statement | Strongly | Agree | Disagree | Strongly |
|---------------------------------------|----------|---------|----------|----------|
| | Agree | n (%) | n (%) | Disagree |
| | n (%) | | | n (%) |
| Taking ART without food will not work | 84 (30) | 70 (25) | 109 (39) | 17 (6) |
| Taking ART is associated with stigma | 129 (46) | 95 (34) | 48 (17) | 8 (3) |
| Taking ART is a waste of time | 8 (3) | 8 (3) | 169 (60) | 95 (34) |

4.5.6 Distribution of respondents' response that ART is associated with stigma

Results of the respondents indicated that out of 280 the proportion of patients who agreed that taking ART is associated with stigma were significant (χ^2 =3.187, P=0.041).

Table 4.16: Distribution of respondents' response that ART is associated with stigma

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 17(34%) | 67(29%) | 2.40= | 0.044 |
| Disagree | 33(66%) | 163(71%) | 3.187 | 0.041 |

4.5.7 Distribution of respondents' response that ART will not work without food

Results of the respondents indicated that out of 280 respondents the proportion of patients who agreed with the statement that taking ART without food will not work were not statistically significant ($\chi^2 = 4.868$, p=0.772)

Table 4.17: Distribution of respondents' response that ART will not work without food

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 11 (22%) | 48 (21%) | 4.060 | 0.552 |
| Disagree | 39 (78%) | 182 (79%) | 4.868 | 0.772 |

4.5.8 Distribution of respondents' response that taking ART is a waste of time

Results of the respondents indicated that out of 280 the proportion of patients who agreed to the statement that taking ART was a waste of time was not statiscally significant ($\chi^2 = 5.274$, P=0.260).

Table 4.18: Distribution of respondents' response that taking ART is a waste of time

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 36 (72%) | 76 (33%) | | |
| Disagree | 14 (28%) | 154 (67%) | 5.274 | 0.260 |

4.5.9 Distribution of respondents' response with regard to their practices while on ART

17% of the respondents agreed that traditional/herbal medicine can be used concurrently with ART, 9% of the patients took their ART anytime so long as they finished their dosage, (22%) shared their ART with other HIV infected patients while (22%) skipped appointments for ART refill.

Table 4.19: Distribution of respondents' responses with regard to their practices while on ART at Amref-Kibra

| Statement | Strongly | Agree | Disagree | Strongly |
|--|----------|---------|----------|----------|
| | Agree | n (%) | n (%) | Disagree |
| | n (%) | | | n (%) |
| I sometimes use Traditional/herbal | 14 (5) | 8 (3) | 157 (3) | 101 (36) |
| medicine instead of ART | | | | |
| I sometimes skip appointments for ART | 28 (10) | 34 (12) | 78 (28) | 140 (50) |
| refill | | | | |
| I usually share ART with other | 42 (15) | 20 (7) | 196 (70) | 22 (8) |
| HIV/AIDS patients | | | | |
| I usually take my medication any time so | 11 (4) | 14 (5) | 196 (51) | 112 (40) |
| long I finish the daily dosage | | | | |

4.5.10 Distribution of respondents' response with regard to the use of traditional/herbal medicine concurrently with ART

Results of the respondents indicated that out of 280 respondents the proportion of patients who agreed to the statement that herbal medicine can be used concurrently with ART were not significant ($\chi^2 = 3.514$, p=0.476).

Table 4.20: Distribution of respondents' response with regard to the use of traditional/herbal medicine instead of ART.

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | n-50 | n=230 | | |
| Agree | 19 (38%) | 58 (25%) | 2.51.4 | 0.456 |
| Disagree | 31 (62%) | 172 (75%) | 3.514 | 0.476 |

4.5.11 Distribution of respondents' response with regard to the sharing of their ART medicine with other HIV infected patients who are not on ART

Results of the respondents showed that out of 280 respondents the proportion of patients who disagreed to the sharing of their ART with other HIV infected patients were statistically significant ($\chi^2=19.049$, p=0.001)

Table 4.21: Distribution of respondents' response with regard to sharing ART with other HIV infected patients.

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | n=50 | n=230 | | |
| Agree | 35 (70%) | 98 (43%) | 10.040 | 0.001 |
| Disagree | 15 (30%) | 132 (57%) | 19.049 | 0.001 |

4.5.12 Distribution of respondents' response with regard to taking ART anytime

Results showed that out of 280 respondents the proportion of patients who disagreed to the statement that one can take ART any time so long as they finished their daily dosage were statistically significant ($\chi^2=13.012$, p=0.011).

Table 4.22: Distribution of respondents's response with regard to taking ART any time

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 34 (68%) | 30 (13%) | 12.012 | 0.011 |
| Disagree | 15 (30%) | 200 (87%) | 13.012 | 0.011 |

4.5.13 Distribution of respondents' response with regard to missing appointments for ART refill

Results of the respondents showed that out of 280 respondents the proportion of patients who agreed to the missing of appointments were not statistically significant ($\chi^2 = 0.568$, p=0.967).

Table 4.23: Distribution of respondents' response with regard to missing appointments

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | n=50 | n=230 | | |
| Agree | 44 (88%) | 29 (13%) | 0.560 | 0.067 |
| Disagree | 6 (12%) | 201 (87%) | 0.568 | 0.967 |

4.5.14 Distribution of respondents' response with regard to adherence practices

Majority of the respondents agreed that indeed being counseled about adherence before starting ART is important (96%), it is important to have someone to remind them to take

ART (75%), while 58% of the respondents agreed that missing a dosage of ART would interfere with the treatment.

Table 4.24: Distribution respondents' response with regard to adherence practices

| Response | Strongly Agree | Agree | Disagree | Strongly Disagree |
|----------------------------------|----------------|----------|----------|-------------------|
| | n% | n % | n % | n% |
| Being Counseled about adherence | 180 (64) | 90 (32) | 5 (2) | 5 (2) |
| before starting ART is important | | | | |
| It is good to have someone to | 130 (46) | 80 (29) | 50 (18) | 20 (07) |
| remind you to take your ART | | | | |
| Missing a dosage of ART would | 56 (20) | 106 (38) | 106 (38) | 11 (4) |
| interfere with treatment | | | | |
| | | | | |

4.5.15 Distribution of respondents' response with regard to adherence counseling

Results of the respondents indicated that out of 280 respondents the proportion of patients who agreed to statement that adherence counseling was important prior to antiretroviral therapy were significantly associated ($\chi^2=21.08$, p=0.000).

Table 4.25: Distribution of respondents' responses with regard to adherence counseling

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 41 (82%0 | 215 (94%) | 21.00 | 0.000 |
| Disagree | 09(18%) | 15 (06) | 21.08 | 0.000 |

4.5.16 Distribution of respondents' response with regard to having something to remind them to take their ART medicine

Results of the respondents indicated that out of 280 respondents the proportion of patients who agreed to the statement that it is important to have treatment support person to remind them to take their ART were significantly associated ($\chi^2 = 9.844$, p=0.043).

Table 4.26: Distribution of respondents' response with regard to having someone to remind them to take their ART

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 35 (70%) | 208 (90%0 | 0.044 | 0.042 |
| Disagree | 15 (30%) | 22 (10%) | 9.844 | 0.043 |

4.5.17 Distribution of respondents' response with regard to missing a dosage of ART would interfere with the treatment.

Results of the respondents showed that out of 280 respondents the proportion of patients who disagreed to the statement that missing a dosage of ART would interfere with the treatment were not significantly associated ($\chi^2 = 3.960$, p= 0.555)

Table 4.27: Distribution of respondents' response with regard to missing a dosage of ART would interfere with the treatment.

| Response | Non adherence | Adherence | χ^2 | P-value |
|----------|---------------|-----------|----------|---------|
| | | | | |
| | n=50 | n=230 | | |
| Agree | 42 (84%) | 216 (94%) | 2.060 | 0.555 |
| Disagree | 08 (16%) | 14 (06%) | 3.960 | 0.555 |

4.5.18 Multivariate Logistic Regression Analysis for knowledge, attitudes, and practices associated with non adherence (Overall Model)

Results from multivariate logistic regression showed that an increase in knowledge statement that only those at the AIDS stage should take ART by one unit leads to an increase in the odds of non adherence by 1.09. This relationship is significant as indicated by a p value of 0.008 which is less than the critical p value (0.05). The results also indicate that an increase in attitude statement that taking ART is a waste of time by one unit leads to an increase in the odds of non adherence by 1.183 times. The relationship is significant as indicated by a p value of 0.048.

In addition, the results revealed that an increase in the practice statement that i usually take my medication anytime so long as I finish my daily dosage by one unit leads to an increase in the odds of non adherence by 1.468 times. This relationship is significant as

indicated by a calculated p value of 0.007. Further, the results showed that an increase in the statement that being counseled about adherence before starting ART is important leads to a decrease in the odds of non adherence by 1.413 times. This relationship is significant as indicated by a calculated p value of 0.047.

Finally the results indicated that an increase in the statement that missing a dosage of ART would interfere with the treatment leads to a decrease in the odds of non adherence by 1.559. This relationship is significant as showed by a calculated p-value of 0.005.

Table 4.28: Overall multivariate Logistic Regression for knowledge, attitudes and practices of respondents' responses

| | В | S.E. | Wald | Df | Sig. | 95% CI | |
|------------|--------|-------|--------|----|-------|--------|-------|
| | | | | | | Upper | Lower |
| Knowledge1 | 0.076 | 0.138 | 0.304 | 1 | 0.581 | 0.82 | 1.4 |
| Knowledge2 | 0.086 | 0.15 | 0.711 | 1 | 0.008 | 0.81 | 1.4 |
| Attitude3 | 0.168 | 0.146 | 5.332 | 1 | 0.048 | 0.88 | 1.6 |
| Practice2 | -0.11 | 0.138 | 0.63 | 1 | 0.427 | 0.68 | 1.18 |
| Practice3 | 0.145 | 0.116 | 1.566 | 1 | 0.211 | 0.92 | 1.45 |
| Practice4 | 0.384 | 0.143 | 7.236 | 1 | 0.007 | 1.11 | 1.94 |
| Ad1 | 0.345 | 0.174 | 3.958 | 1 | 0.047 | 1.00 | 1.98 |
| Ad2 | 0.155 | 0.157 | 0.971 | 1 | 0.324 | 0.86 | 1.59 |
| Ad3 | 0.444 | 0.159 | 7.751 | 1 | 0.005 | 1.14 | 2.13 |
| Constant | -6.443 | 1.429 | 20.333 | 1 | 0.000 | | |

4.6 Treatment related information for the study participants

Baseline clinical characteristics for the study subjects were extracted from patient files (Appendix 111). Majority of the patients had initial CD4 cell count of 201-250 (24.4%) followed by 151-200 (23.0%) before ART initiation. Initial CD4 cell count was considered to be important in this study due to the fact that ART adherence is associated with immunological recovery in HIV- infected patients, and good adherence contributes to greater growth of CD4 cell count. Patients with low CD4 cell count (<200 cells/µ1.) at the time of ART initiation are more likely to exhibit poor adherence due to the presence of opportunistic infections. In addition, inadequate adherence to treatment is associated with detectable viral loads, declining CD4 cell count, disease progression, episodes of opportunistic infections and poorer health outcomes (Spire *et al.*, 2002).

Pill burden can often affect any medication. A majority of the patients (53.6%) had suffered from opportunistic infections while only 7.1% of the patients had significant co morbid illness. Most of the patients were either on zidovudine-lamivudine-nevirapine (46.4%) or tenofovir-lamivudine-efavirenz regimen (35.7%). The type of regimen being taken would determine the side effects. At least 3.6% of the patients had undergone treatment interruption during the 12 months on antiretroviral treatment therapy.

Table 4.29: Treatment related information of HIV patients at Amref-Kibra community-based health centre

| Variables | Categories | N | Frequency % |
|--------------------|-------------|-----|-------------|
| Initial CD4 cell | <50 | 8 | 3.0 |
| count (cells/mm3) | 51-100 | 17 | 6.0 |
| | 101-150 | 36 | 12.8 |
| | 151-200 | 64 | 23.0 |
| | 201-250 | 69 | 24.4 |
| | 251-300 | 32 | 11.3 |
| | 301-350 | 35 | 12.5 |
| | 351-400 | 11 | 4.1 |
| | > 400 | 8 | 2.8 |
| Presence of | No | 150 | 53.6 |
| opportunistic | Yes | 130 | 46.4 |
| infections | | | |
| Significant co | No | 260 | 92.8 |
| morbid illness | Yes | 20 | 7.1 |
| Initial first-line | D4T/3TC/NVP | 4 | 1.4 |
| regimen | D4T/3TC/EFV | 2 | 0.7 |
| | AZT/3TC/NVP | 130 | 46.4 |
| | AZT/3TC/EVF | 30 | 10.7 |
| | TDF/3TC/EFV | 100 | 35.7 |
| | TDF/3TC/NVP | 14 | 5.0 |
| History of | No | 270 | 96.4 |
| treatment | Yes | 10 | 3.6 |
| interruption | | | |

CHAPTER FIVE

DISCUSSION AND CONCLUSIONS

5.1 Discussion

The current study determined the prevalence of non-adherence and factors associated with it in Kibra slums, Nairobi County. Prevalence of non adherence in this study (18%) is comparable to that found in the African continent which was 23% (Mills *et al.*, 2006), and that which was done in Southwest Ethiopia by Amberbir *et al* 2008), but inconsistent with the findings of (Ellis *et al.*, 2006) in Kibra slums, Nairobi, whose study reported prevalence of non adherence at (48%). The inconsistency with the findings of Kibra is attributed to differences in treatment periods (2006) when ART knowledge among patients and health care workers was low. The study by Ellis *et al.*, 2006 recommended a community-based clinic with committed healthcare workers to empower economically disadvantaged population to be adherent to ART. The current study was carried out in Amref-Kibra community based health centre in which non-adherence has greatly improved from the previous 48% by Ellis *et al.*, to the current 18%. This is due to the systems that has been put in place including; adherence counseling prior to starting ART, formation of treatment support group and treatment monitoring among HIV patients on ART.

The study revealed that majority of the respondents (62%) agreed that being counseled about ART adherence was important. Effective counseling is needed to ensure that patients adhere to their drug regimen. HIV infected patients need to be constantly reminded of the lifelong nature of ART and that there is no need to experience shame while on ART. Various studies have demonstrated ART to be the only available effective form of therapy for HIV/AIDS (Idoko *et al.*, 2006). Non-adherence may eventually undermine the dramatic improvement in HIV-related parameters seen in

resource-rich countries and expected in developing countries as antiretroviral therapy becomes more widely available.

The main reasons for non-adherence were forgetting to take medicine, side effects, pill burden, and stigma which were similar to other studies in Jimma- Nigeria by Endrias *et al.*, 2008 and in Kenya by Antony *et al.*, 2011. Forgetfulness was the most common reason for non-adherence among the respondents. A study done in Southwest Ethiopia showed that patients who use memory aids were three times more likely to be adherent than those who did not (Amberbir *et al.*, 2008).

Side effects were another factor that influenced non-adherence in this study. Similarly, a study done in North-West Ethiopia indicated that the reasons for missing doses were forgetfulness and side effects of antiretroviral therapy drugs (Tsega *et al.*, 2015). In addition, those patients taking less pill burden were more likely adherent. The finding is comparable with previous reports that pill burden likely decreases the ART adherence (Sarna *et al.*, 2008). This might be associated with when a number of pill increases, it may subject the patients to experience more adverse effects from the medications which potentially lead them to skip their treatment.

Lack of disclosure was another factor which influenced non-adherence especially among married couples (13.6%). Those who did not disclose about own sero-status was found to be associated with adherence similar to other studies conducted in different parts of Ethiopia (Amberbir *et al.*, 2008). When there is no self-disclosure, the persons may fear to take their treatments when other people present. In such case there is need to develop skill to maintain adherence in the non-disclosure state or design a way for disclosure.

Depressed patients (12.5%) in this study are less likely to adhere than those non-depressed. Other comparable findings were also documented from within and outside of the country (Tefera *et al.*, 2011). This might be explained as that those depressed patients usually experience hopelessness and demoralization which can expose them

skipping or forgetting their regular treatment. This finding has a strong implication that there is a need to design to screen patients on a regular bases and then provide them appropriate counseling.

Persons living with HIV are often subject to stigmatization and discrimination. It has been noted that stigma against HIV maybe barrier to medication adherence mainly due to the interaction between adherence and disclosure (Klitzman *et al.*, 2004). If patients are seen by members of their social constellation such as neighbors, family members, of friends, to be taking ART, this is likely to convey a signal that are HIV positive or living with AIDS. In this study, 8.2% of the patients felt stigmatized while taking ART. Other factors that may affect adherence include attempts to hide the medication, change dosing schedules, or suppress observable side effects of treatment. It has been suggested that even disclosure to others may result in negative attitudes that may inhibit adherence (Klitzman *et al.*, 2004).

16.1% (45) of respondents residing within walking distance from home to the clinic exhibited non-adherence. These findings together with social stigma with ART use suggested that most respondents who accessed free therapy in clinics within walking distance to their homes did so due to lack of choice; speculatively, could not afford transport to alternative ART clinics. Patients lacking psychosocial support from family exhibited poor adherence (7.5%). This implies that consistent psycho-social support have a positive impact on ART adherence. The results are consistent with the findings of Holstad *et al.* (2006) who found that positive social and family was associated with relatively good treatment adherence.

The study also determined how socio-demographic and socio-economic influence antiretroviral therapy among HIV patients. This study considered age, gender, education, marital status and average monthly income. Proportion of female in this study was two-fold that of male and is similar to the proportion of HIV/AIDS reported in Kenya (NACC, 2008). However, gender did not influence non-adherence to ART in Kibra.

These findings correlated with findings of other studies (Byakika *et al.*, 2005). Married couple in this study influenced non-adherence, this finding is similar also to Byakika *et al.*, 2005 who found an association between marital status and non-adherence to ART in Uganda, while Weiser et al. in Botswana did not.

Social economic factors did not significantly influence adherence in this study. Findings with respect to average monthly income were consistent with the findings of Orrell *et al.*, 2003 in South Africa but inconsistent with findings of Byakika *et al* in Uganda where patient paid for ART. However, a study done in Kenya found that employed patients who had a higher monthly income were less adhered to treatment (Antony *et al.*, 2011). The explanation of this may indicate that lower level income can expose them to various psychological issues which can hamper adherence. Findings with formal education were consistent with the findings of Weiss *et al.*, 2003 in Botswana but inconsistent with the findings of Carballo *et al.*, 2004 in spain where understanding of treatment regimen was poor.

It was evident from the study that majority of respondents had CD4 cell count of 101-199 (44.6%), followed by 50-100 for (28.9%) of the respondents. CD4 cell count at the time of ART initiation is an important determinant of the degree of immunological and virological response (Staszewski *et al.*, 1999), as well as subsequent risk of morbidity and mortality (Bonnet *et al.*, 2002). In adequate to adherence to treatment is associated with detectable viral loads, declining CD4 cell count, disease progression, episodes of opportunistic infections and poorer health outcomes (Spire *et al.*, 2002).

The baseline CD4 count, second only to subsequent medication adherence, is the most important predictor of clinical progression and survival after ART initiation (Bonnet *et al.*, 2002). A recent study in the Netherlands suggested that entry into care with low CD4 counts, explained a substantial portion of the variation in mortality rates across HIV care and treatment centers (Smit *et al.*, 2008).Many studies have shown a strong

correlation between adherence and clinical outcomes and/or laboratory makers (notably CD4 cell count.

In this study 9.9% (28) patients with CD4 cell count <250 exhibited non-adherence as compared to 22 (8%) of those with CD4 cell count>250. A cording to a study by Rais *et al.*, 2013), 60% of patients who were non-adherence and had low CD4 cell at the time of initiation, also suffered from different opportunistic infections. According to Rais *et al.*, among individuals with CD4 cell count <200 cells/cmm, non-adherence increased the mortality risk by 11 times whereas for those with cell count 200+ cells/cmm, non-adherence increases the risk by 3 times. This indicates that the baseline CD4 cell count can influence the effect of adherence on survival of HIV infected individuals. Therefore initiating individuals as soon as they become eligible is important for the success of ART program.

Non adherence has been found to diminish the immunological benefit of ART and increase in AIDS-related morbidity and mortality and hospitalization. It was revealed that patients who did not encounter opportunistic infections due to a higher CD4 cell count had more adherences to their treatment which is consistent with other study in United States of America by Dean *et al.*, 2002). This might show the multiple occurrences of the infections potentially increase pill burden which can be associated with increased level adverse reaction so that influence the treatment adherence.

Knowledge about HIV/AIDS has been identified as a powerful tool to prevent the transmission of this disease. Unfortunately, this knowledge about the disease has not resulted in appreciable changes in attitudes or in behavior modifications in the population (Ogbuji, 2005). The study revealed that majority of the respondents had good knowledge about HIV/AIDS and ART. However, a fair propotion of the respondents had poor knowledge about ART. For example, approximately 84% agreed that only those with AIDS should take ART while 94% of the respondents agreed that ART should be

taken only when one falls sick. These findings indicate that there is an urgent need to educate HIV infected patients about ART.

Previous studies have shown that the level of knowledge about the mode of transmission of HIV affects attitudes about HIV/AIDS transmission (Almeida *et al.*, 2009). Moreover, a proportion of respondents did not have the basic knowledge of the purpose of ART, which is to prolong and improve the quality of life of patients by increasing their CD4 cell count and reducing their viral load (Monjok et al., 2010). This lack of knowledge about HIV/AIDS and ART is probably a concern not just for HIV infected people but for the general population and perhaps a reason for continuing HIV transmission in our population.

Patients in this study generally had a positive attitude towards ART. However, 87% of the respondents agreed that ART was awaste of time. This belief could seriously hinder the ability of HIV infected patients to look into the future with a positive attitude and may affect their adherence to therapy. A positive attitude has been shown to contribute to good adhrence to therapy (Cherurat *et al.*, 2010). 69% of the respondents agreed that ART will not work without food. Approximately 57% of the respondents felt that taking ART for their lifetime was tiring. A positive disposition about HIV status and adherence to ART are critical to achieve the expected responses and to prevent drug resistance.

The perception of stigma by HIV infected patients showered that unacceptably high proportion of patients were upset by people seeing them in the antiretroviral clinic (80%), took ART anytime so long as they finished the dosage (88%). These findings suggest that although treatment is available, people infected with HIV might not benefit from this treatment because of self-stigmatization. These people are likely to stay away from treatment when they feel stigmatized. Hence, clinics need to be more patient-friendly and conducive to treatment which can be done by involving more HIV infected patients in their own care and ongoing counseling.

5.2 Study limitations

The study determined factors significantly associated with non adherence based on the CASE adherence tool. Although this method can estimate adherence, it can still be inaccurate due to the fact that not all patients would recall having missed a dose of ART. In addition, being a single-centered study, the results may not also be generalized to all facilities in Kibra slums. Thus, I suggest further studies with a more specific objective measure of adherence such as checking of serum drug levels of patients and a multiple site study be carried out.

5.3 Conclusions

- The ART non-adherence was 18%
- It was revealed that forgetfulness, side effects, Pill burden, Depression and Stigma were associated with non-adherence
- Socio-demographic and socio-economic factors did not significantly influence non-adherence in this study.
- 9.9% of patients with CD4 cell count<250 before ART initiation exhibited nonadherence compared with 22 (8%) of those with CD4 cell count of >250. This
 indicates that baseline CD4 cell count can influence the effect of adherence on
 the survival of HIV infected individuals.
- From multivariate logistic regression analysis, the study also showed that
 inadequate knowledge about the role of ART in HIV management; poor attitudes
 and practices are associated with non adherence.

5.4 Recommendation

Due to the complex arrays of factors associated with non-adherence, no single strategy is likely to be effective for every patient. Moreover, in order to maximize the benefits of ART, patients should be educated on the need of adhering to the right dose at the right

time. Forgetfulness was the most common reasons for non-adherence to ART in this study. Therefore, adherence counseling and health information dissemination need to include strategies to minimize forgetfulness using memory aids such as pill boxes and written schedule. In addition, further studies on adherence rate and its determinants with multiple adherence measurements to resolve the barriers to non-adherence are also recommended. Initiating ART for individuals as soon as they become eligible is also recommended for the success of ART program.

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APPENDICES

Appendix I: Consent form

There are an increasing number of HIV patients failing antiretroviral therapy. Although these patients are being monitored immunologically and virologically, there is need to determine factors that are associated with treatment failure. This study purposes to document factors associated with non adherence to antiretroviral therapy among HIV patients.

Purpose of the study

The main objective of this study was to determine factors associated with non adherence to antiretroviral therapy among HIV infected patients at Amref- Kibra community-based health centre, Kibra slums, Nairobi County.

Part B: Participation Consent Form

Please read the information sheet (PART A) and if there are any questions you have which are unclear to you regarding this study, please feel free to ask the investigator prior to signing the consent form.

Participation statement

| access to normal health care and management. I therefore consent voluntarily t | to |
|--|----|
| participate in this study. | |
| | |
| Name of the participant or respondentSignature | |
| | |
| Name of the investigatorSignature | |
| | |
| Date | |

Appendix II: Questionnaires

SECTION 1: Socio demographic and socio economic characteristics of study participants

| 1. Gen | der | |
|---------|---|---------------------|
| | Female | |
| | Male | |
| 2. Date | e of birth | Age |
| 3. Wha | at is the highest level of education yo | ou have completed? |
| i. | Never been to school | |
| ii. | Primary school education | |
| iii. | Secondary school | |
| iv. | Tertiary education | |
| 4. Wha | at is your marital status? | |
| i. | Married to one partner | |
| ii. | Widow or widower | |
| iii. | Single | |
| iv. | Divorced or separated | |
| 5a. Ho | w many people do you reside with, e | excluding yourself? |
| | i. 0 | |
| | ii. 1 | |
| | iii. 2 | |

| iv. | 4-5 | |
|-----------------|-------------------------------|---|
| v. | ≥6 | |
| Of these, how | many are children? | |
| | | |
| 5b.What is th | e nature of relationship to t | hose you reside with? (You may check more |
| than one option | on. | |
| i. | Wife/ husband/partner | |
| ii. | Children | |
| iii. | Friends | |
| iv. | Relatives | |
| v. | Other | |
| Please specif | y | |
| 6. How many | people are you supporting fi | nancially (excluding yourself)? |
| i. | 0 | |
| ii. | 1 | |
| iii. | 2-3 | |
| iv. | 4-5 | |
| v. | 6-7 | |
| vi. | ≥8 | |
| 7a. Are you li | ving in Kibra? | |
| i. | Yes | |
| ii. | No | |

If response is no, please specify where you live and skip the next question 7b and go to question 8.

| 7b. how long | have you been living in Kibra? |
|-----------------|---|
| Please specify | yMonths ORyears |
| | |
| 8. How long d | loes it take you to reach the clinic from your residence? |
| Please specify | yhours |
| 0.11 | |
| • | ou get to the clinic (main mode of transportation) e.g. walking, public |
| transport etc.? | |
| Please specify | y • • • · · · · · · · · · · · · · · · · |
| | |
| 10. How mucl | h do you usually pay for return travel to the clinic? |
| Please specify | yKES |
| | |
| 11. What is yo | our present occupation? |
| i. | Employed |
| ii. | Self-employed |
| | |
| iii. | Casual labor |
| iv. | Unemployed |
| v. | Student |
| | |
| vi. | Housewife |
| vii. | Other |
| | |
| Please specify | y |

If you are not currently working, please go to the next page

| 12. How much | time do you have to miss f | rom work to attend the clinic? |
|--------------------------------|--|--------------------------------|
| i. ii. iii. iv. v. | Less than 2 hours Up to half a day A whole day More than one day Not applicable th do you earn in a month? Less than KES 1000 KES 1001-5000 KES 5001-10,000 More than KES 10,000 Not willing to disclose | rom work to attend the clinic? |
| vi. 13b.What is yo | Not certain our average household incom | me per month? |
| i. | Less than 1000 | |
| ii. | KES 1001-5000 | |
| iii. | 5001-10,000 | |
| iv. | KES 10,001-20,000 | |
| v. | More than KES 20,000 | |
| vi. | Not willing to disclose | |
| vii. | Not certain | |

SECTION II: Knowledge, attitudes and practices of HIV positive patients on ART

(A) KNOWLEDGE

This section attempts to establish study participants knowledge and how it influences adherence Use the likert scale. The response scale for the questions is as below:

1= Strongly Agree, 2= Agree, 3= Disagree, 4= Strongly Disagree

| 1 | Antiretroviral | Strongly agree | Agree | Disagree | Strongly |
|---|---------------------------------|----------------|-------------|-------------|----------|
| | treatment helps to prolong life | □ 1 | □ 2 | □3 | disagree |
| | | | | | □ 4 |
| 2 | Only those at the | Strongly agree | Agree | Disagree | Strongly |
| | AIDS stage should | | | | disagree |
| | take ART | \Box 1 | \square 2 | \square 3 | |
| | | _ | | | □ 4 |
| 3 | Antiretroviral | Strongly agree | Agree | Disagree | Strongly |
| | therapy reduces viral | | | | disagree |
| | load | \Box 1 | \square 2 | □ 3 | |
| | | | | | □ 4 |
| 4 | ART consists of drugs | Strongly agree | Agree | Disagree | Strongly |
| | to cure HIV | | | | disagree |
| | | \square 1 | \square 2 | □ 3 | |
| | | | | | □ 4 |
| 5 | Antiretroviral | Strongly agree | Agree | Disagree | Strongly |
| | therapy helps prolong | | | | disagree |
| | lives | \square 1 | \square 2 | □ 3 | |
| | | | | | □ 4 |

(B) ATTITUDE

This section attempts to establish the effect of attitude of study participants with regard to ART and how it influences adherence

Use the likert scale. The response scale for the questions is as below:

1= Strongly Agree, 2= Agree, 3= Disagree, 4 = Strongly Disagree

| 1 | Taking ART is a | Strongly agree | Agree | Disagree | Strongly |
|---|-------------------|----------------|-------------|----------|----------|
| | waste of time | | | | disagree |
| | | □ 1 | \square 2 | □ 3 | |
| | | | | | □ 4 |
| 2 | ART is associated | Strongly agree | Agree | Disagree | Strongly |
| | with stigma | | | | disagree |
| | | □ 1 | \square 2 | □ 3 | |
| | | | | | □ 4 |
| 3 | ART will not work | Strongly agree | Agree | Disagree | Strongly |
| | without food | | | | disagree |
| | | □ 1 | \square 2 | □ 3 | |
| | | | | | □ 4 |

(C) PRACTICES

This section attempts to establish practices of study participants while taking ART

Use the likert scale. The response scale for the questions is as below:

1= Strongly Agree, 2= Agree, 3= Disagree, 4 = Strongly Disagree

| 1 | Traditional/ herbal | Strongly | Agree | Disagree | Strongly |
|---|--------------------------|----------|-------------|-------------|----------|
| | medicine can be used | agree □1 | | | disagree |
| | concurrently with ART | | \square 2 | \square 3 | |
| | | | | | □ 4 |
| 2 | Sharing ART with other | Strongly | Agree | Disagree | Strongly |
| | HIV infected patients | agree □1 | | | disagree |
| | | | \square 2 | \square 3 | |
| | | | | | □ 4 |
| 3 | Taking ART anytime so | Strongly | Agree | Disagree | Strongly |
| | long as one finishes the | agree □1 | | | disagree |
| | dosage | | \square 2 | □ 3 | |
| | | | | | □ 4 |
| | | | | | |
| 4 | Skipping appointments | Strongly | Agree | Disagree | Strongly |
| | for ART refill | agree □1 | | | disagree |
| | | | \square 2 | □ 3 | |
| | | | | | □ 4 |

(D) ADHERENCE

This section attempts to establish respondents' views on ART adherence Use the Likert scale. The response scale for the questions is as below:

| 1. Being given adherence | Strongly | Agree | Disagree | Strongly |
|---|----------|-------|----------|----------|
| | agree | | | disagree |
| Counseling before starting ART is | | | | |
| important | | | | |
| 2. It is good to have someone to remind | Strongly | Agree | Disagree | Strongly |
| them to take their | agree | | | disagree |
| | | | | |
| ART medicine | | | | |
| 3. Missing a dosage of ART would | Strongly | Agree | Disagree | Strongly |
| interfere with the treatment | agree | | | disagree |

SECTION III: NON-ADHERENCE: CASE ADHERENCE INDEX QUESTIONNAIRE

- 1. How often do you feel that you have difficulty taking your HIV medications on time? By `on time 'we mean no more than two hours before or two hours after the time your doctor told you to take it.
- 4 Never 3 Rarely 2 Most of the time 1 All the time
- 2. On average, how many days per week would you say that you missed at least one dose of your HIV medications?
 - 1 Everyday 2 4-6 days/week 3 2-3 days/ week 4 Once a week 5 Less than once a week 6 Never
- **3.** When was the last time you missed at least one dose of your HIV medications?

1 Within the past week 2 1-2 weeks ago 3 3-4 weeks ago 4 between 1 and 3 months ago 5 More than 3 months ago 6 Never

SECTION IV: REASONS FOR NO-ADHERENCE

The following reasons made you skip the medication (To mark the box with (1) for Yes or (2) for No.

| 6 Lack of disclosure | |
|------------------------------------|--|
| 7. Pill burden | |
| 8. Side effects | |
| 9. Lack of food | |
| 10. Hospitalized | |
| 11. Depressed | |
| 12. Shared pills | |
| 13. Proximity to the clinic | |
| 14. Simply forgot | |
| 15. Alcohol use | |
| 16. Stigma | |
| 17. Lack of care/ support | |
| 18. Cost of antiretroviral therapy | |

| 19. Clinic not accessible | L | |
|-------------------------------------|------|--|
| 20. Other | | |
| (Please specify) | | |
| Name of the investigator/Researcher | | |
| Signature | Date | |

Appendix III: Treatment related information of HIV infected patients at Amref-Kibra Community-Based Health centre.

(Extracted from their health records)

| 1. Months on ART |
|--|
| 2. History of treatment interruption |
| 3. Initial CD4 count |
| 4. WHO staging at the time of ART initiation |
| 5. Initial first-line regimen |
| 6. Viral load after 6 months of antiretroviral treatment |
| 7. Presence of opportunistic infections |
| 8. Significant co morbid illness |

Appendix IV: Research Authorization Permit



Appendix V: Ethical Clearance



UNIVERSITY OF NAIROBI COLLEGE OF HEALTH SCIENCES P O BOX 19676 Code 00202 Telegrams: varsity (254-020) 2726300 Ext 44355

Ref: KNH-ERC/A/22

Zipporah K. Momanyi TM306-1043/2011 JKUAT



KNH/UON-ERC Email: uonknh_erc@uonbi.ac.ke Website: www.uonbi.ac.ke



KENYATTA NATIONAL HOSPITAL P O BOX 20723 Code 00202 Tel: 726300-9 Fax: 725272 Telegrams: MEDSUP, Nairobi

27th January 2015

Research Proposal: Factors associated with antiretroviral treatment failure among HIV positive patients in Kibera slums, Nairobi county (P625/10/2014) patients in Kibera slums, Nairobi county

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and $\underline{\textbf{approved}}$ your above proposal. The approval periods are 27^{th} January 2015 to 26^{th} January 2016.

This approval is subject to compliance with the following requirements:

- Only approved documents (informed consents, study instruments, advertising materials etc) will be used. All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.

 Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events b)
- whether related or unrelated to the study must be reported to the KNH/UoN ERC within 72 hours of
- Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period.
- (Attach a comprehensive progress report to support the renewal).

 Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
- Submission of an executive summary report within 90 days upon completion of the study

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

For more details consult the KNH/UoN ERC website www.erc.uonbi.ac.ke

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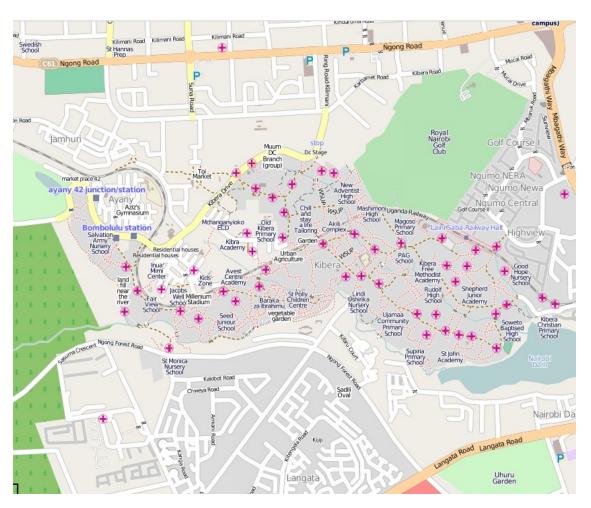
Yours sincerely

PROF. M. L. CHINDIA SECRETARY, KNH/UON-ERC

c.c. The Principal, College of Health Sciences, UoN The Deputy Director CS, KNH The Assistant Director, Health Information, KNH The Chairperson, KNH/UON-ERC Supervisors: Dr. Simon Karanja, Dr.Charles Mbakaya

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Appendix VI: A Map Of Kibra Slums



Source: Google maps

https://www.google.com/search?q=latest+map+of+Kibera+A4&tbm=isch&tbo=u&source=univ&sa=X&ved=0ahUKEwjdm4zBysbRAhWEWhQKHR5BCYYQsAQIGg&biw=1366&bih=657#imgrc=P5mEJrM6V01eyM%3A