

**FACTORS AFFECTING LONG TERM RETENTION OF ADULT PATIENTS TO
CHRONIC HIV CARE IN SIAYA AND BONDO COUNTY HOSPITALS**

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(SPH/PGH/1029/11)

**A Thesis submitted in partial fulfillment of the award of the requirements for the
degree of Master of Public Health of the School of Public Health, Moi University.**

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Declaration

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Declaration by Supervisors

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Dedication

I dedicate this work to my family and many friends. A special feeling of gratitude to my loving parents, Narman and Euphemia whose words of encouragement and consistent support has kept me going. My siblings, Linda, Terence and Basil for their special contribution to this work.

I also dedicate this thesis to my many friends who have supported me throughout the process. I will always appreciate all they have done.

I dedicate this work and give special thanks to my wife Jacky for always being there for me.

Abstract

Background

Long term retention to HIV care is critical to reduce HIV related morbidity and mortality, reduce incidence of new infections and reduce development of antiretroviral therapy (ART) resistance. The main objective of this study was to assess factors affecting long term retention to HIV care in a HIV cohort in Bondo and Siaya.

Methods

This was a retrospective cohort study conducted in Siaya and Bondo district hospitals. The study sampled 377 patients who were enrolled to care between 1st January 2010 and 1st July 2010. Long term retention was defined as remaining engaged in care for 24 months. Data was analyzed using SPSS computer software. Descriptive statistics was done for all variables. Bivariate analysis was done using Chi-Square test. Kaplan-Meier survival method was used to estimate probability of retention. Logistical regression model was used to predict determinants of long term retention.

Results

The mean age of participants was 35.1 years (\pm 11.23); and 65% were female. After 24 months of follow-up after enrollment into HIV care, half (58.4%) of the patients were still active in care; 61 (16.2%) of the patients had transferred out to other facilities; 96 had either died (2.7%) or were lost to follow-up (22.8%). Using chi-square test, retention was significantly associated with: occupation status at enrolment($p= 0.030$), WHO stage at enrolment($p =0.031$), CD4 count at enrolment($p= 0.000$) and marital status at enrollment ($p =0.024$). Logistic regression analysis found, WHO stage 1 (AOR 3.611 95%CI 1.020-12.779 $P=0.04$) and CD4<200(AOR 0.304 95%CI 0.0106-0.873 $P=0.03$) were associated with increased and decreased likelihood of retention respectively.

Conclusion and Recommendation

Only half the patients in care at Siaya and Bondo DH were retained in long term care. WHO stage 1 disease at enrolment was associated with increased likelihood of retention and CD4<200/uL was associated with decreased likelihood of retention, There is need to ensure early HIV diagnosis and linkage to care before deterioration of immune and clinical status. Targeted interventions for patients enrolling with advanced HIV disease are key to ensure they remain in care.

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List of Abbreviations

AIDs - Acquired immunodeficiency Syndrome

ART – Anti Retroviral Therapy

CCC - Comprehensive Care Clinic

CD4 - Cluster of differentiation

DASCO - District AIDS and STD coordinator

HIV - Human Immunodeficiency Virus

IPT - Isoniazid Preventive Therapy

LTFU - Lost to follow up

NACC - National AIDS Control Council

NASCOP - National AIDS and STD Control Program

PITC - Provider initiated counselling and testing

PLWHIV - People living with HIV

PMTCT - Prevention of Mother to Child Transmission

TB - Tuberculosis

UNAIDS - United Nations joint program on HIV AIDS

WHO - World Health Organisation

Definition of Terms

Long term retention – Ensuring that the client continues to receive appropriate services through the continuum of HIV care. In this document, long term retention refers to ensuring the client is engaged in care for at least 24months from the time of enrollment into care (Fox *et al.*, 2012, WHO, 2011)

Attrition – Discontinuation from active engagement in the care continuum due to any reason (Fox *et al.*, 2012)

Continuum of care – Continuum between diagnosis of HIV to initiation and maintenance of lifelong ART.

Loss to follow-up – Patients who are lost from the continuum of care for 90 days or more with unknown outcomes.

Cormorbidity – Having two or more illnesses concurrently.

Pre-ART period – The Period between enrollment to care and initiation of ART.

Pre ART care – All services provided to patients between testing positive for HIV and dispensing of the first dose of ARVs (Fox *et al.* ,2012).

ART period – The Period encompassing initiation and maintenance of lifelong ART.

Enrollment into care – Registration in an ART clinic for follow-up care.

Entry point into care – Service point in the health facility where the diagnosis of HIV is made.

Retention in care- ensuring that the client continues to receive appropriate services through the continuum of care

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May God bless you all!

CHAPTER ONE

INTRODUCTION

1.1 Background

The African continent is the most affected by HIV and AIDS. Sub-Saharan Africa is the most affected region having 68% of the total population of people living with HIV (WHO, 2011). The Kenya Aids indicator survey (KAIS 2012)) showed that 1,192,000 people were living with HIV in 2012 with 5.6% of adults in the 15-64 age bracket. HIV prevalence among adults varies by region with the highest prevalence reported in Nyanza and lowest prevalence reported in Eastern North region respectively. According to the KAIS report, Siaya County ranks 3rd with a prevalence of 17.1% (KAIS 2012). Since the early 1980s when the first diagnosis of HIV was made in Kenya, HIV has claimed the lives of at least 1.7 million Kenyans. In 2011, an estimated 49,126 people in Kenya died of AIDS-related causes (NACC/NASCOP, 2011)

Availability and affordability of antiretroviral therapy (ART) has seen most sub-Saharan countries scale up access to HIV treatment and care. Globally, by the end of 2011, over 8 million people had access to ART in low and middle-income countries. (WHO, 2011) In Kenya, 63% of adults who were eligible for ART were receiving it in 2011 (KAIS, 2012). ART is taken for life and patients should be retained in care for as long as possible to minimize chances of drug resistance and ensure optimum benefits of treatment. Retention in HIV care entails ensuring that the client continues to receive appropriate services through the continuum of care. WHO defines long term retention as continuous engagement of an HIV infected person in the care continuum beyond 24 months (WHO, 2011). Retention in care can be defined from the moment of initial engagement in care

when a person with HIV is linked successfully to services, assessment for eligibility, initiation on ART and retention in lifelong ART care. The period from diagnosis to successful linkage to care is included by some authors (Fox *et al.*, 2012, Giordano *et al.*, 2007). The period between HIV diagnosis and initiation to ART is the pre-ART phase, while the period after initiation of ART is the ART phase. The pre-ART phase can further be divided into three stages; stage 1 which is the period from HIV diagnosis to completion of the initial ART eligibility assessment; stage 2 which is the period from completing the first ART eligibility assessment to ART eligibility; and stage 3 which is the period from eligibility to ART initiation (Fox *et al.*, 2012).

In order to ensure patients are retained in care for as long as possible an active and deliberate service delivery response is necessary. This response starts with knowledge of the various factors impacting on retention. Strategies have been put in place to improve retention to care. These include: linking patients to treatment “buddies”, active and timely follow-up after missed appointments, psychosocial support services and provision of food supplements to food-insecure patients (NACC/NASCOP, 2011).

In Kenya, retention into care is still a public health concern as roughly one in three patients on ART are no longer enrolled in care 2 years after starting therapy (NACC/NASCOP 2011). Retention to care is thought to be low due to various factors that range from patient factors to health facility-based factors. It is for this reason that we conducted this study to document those factors that strongly affect retention.

1.2 Statement of the problem

Long term retention in care is required to ensure optimal clinical outcomes in patients with HIV infection (Geng *et al.*, 2010. Mannheimer *et al.*, 2005). For ART naive patients, poor retention prevents ongoing immunologic and clinical evaluation. Those already on ART might not be adherent to treatment. Poor adherence is an important factor in the development of drug-resistant HIV strains (Boden *et al.*, 1999).The end result of poor retention will be increased morbidity and mortality and an increase in transmission of HIV.

The desire of programs would be to retain all patients for as long as possible. Long term retention into care has remained a challenge in sub Saharan Africa as more patients drop out of the continuum of care due to loss to follow up and death with time (WHO, 2007). In Kenya, long term retention is still a public health problem as roughly one in three patients on ART are no longer enrolled in care two years after starting therapy (NACC/NASCOP, 2011).

The magnitude and determinants of patient retention vary substantially and therefore encouraging the conduct of locally relevant research to inform programmatic decisions (Geng *et al.*,2011). Various studies (Ochieng-ooko *et al.*,2010, Karcher *et al.*,2007 Massaquoi *et al.*,2009) have shown that multiple factors might impact on retention. These factors can be classified as patient factors, health facility based factors and community/environmental factors.

1.3 Justification of the study

Long term retention to care is of public health importance (Horstmann *et al.*,2009). Retention of pre ART patients ensures they benefit from regular checks to determine their

eligibility for initiation on ART. Prompt initiation of ART in turn reduces HIV-related morbidity and mortality. Long-term retention of pre ART patients will also ensure they benefit from the prevention messages that target the HIV infected persons. On the other hand, retention of ART patients ensures patients adhere to ART and thus guard against drug resistance and treatment failure. Therefore, retaining HIV-infected patients has the potential to help contain health care costs by improving HIV-specific health outcomes and reducing emergency hospital visits and admissions (Gill *et al.*,2000). Recent studies (Cohen MS *et al.*,2012, Reynolds *et al.*,2009, Sullivan *et al.*,2009) have shown the role of ART treatment for prevention of HIV transmission. Ensuring retention of clients on ART enhances optimizing on the benefits of ART for prevention of HIV transmission.

Improving patient retention at programmatic and policy levels requires a better understanding of factors that contribute to patients falling out of care, followed by an assessment of factors that can be addressed (Horstman *et al.*,2009).

This study set out to assess factors affecting long term retention both for ART and pre ART patients. Findings from this study will aid HIV programs design innovative interventions that will ensure patients are retained to care thus ensuring satisfactory outcomes.

1.4 Research Questions of the Study

The study sought to answer the following research questions:

1. What is the retention rate, at 24-months, among HIV infected adults enrolled in care in Siaya and Bondo District Hospitals?

2. What factors affect the long term retention of HIV infected adults to long term HIV care in the 2 hospitals?

1.5 Objectives of the Study

1.5.1 Broad Objective

To assess factors that affect long-term retention of adult patients to HIV care.

1.5.2 Specific Objectives

1. To determine the retention rates, at 24 months, among HIV infected adults enrolled in care in Siaya and Bondo District Hospitals.
2. To determine the factors affecting long term retention of HIV infected adult patients in HIV care.

1.6 Null hypothesis

1. Health facility based factors have no association with long term retention to care of adult HIV infected patients.
2. Patient factors have no association with long term retention to care of adult HIV infected patients.

CHAPTER TWO

LITERATURE REVIEW

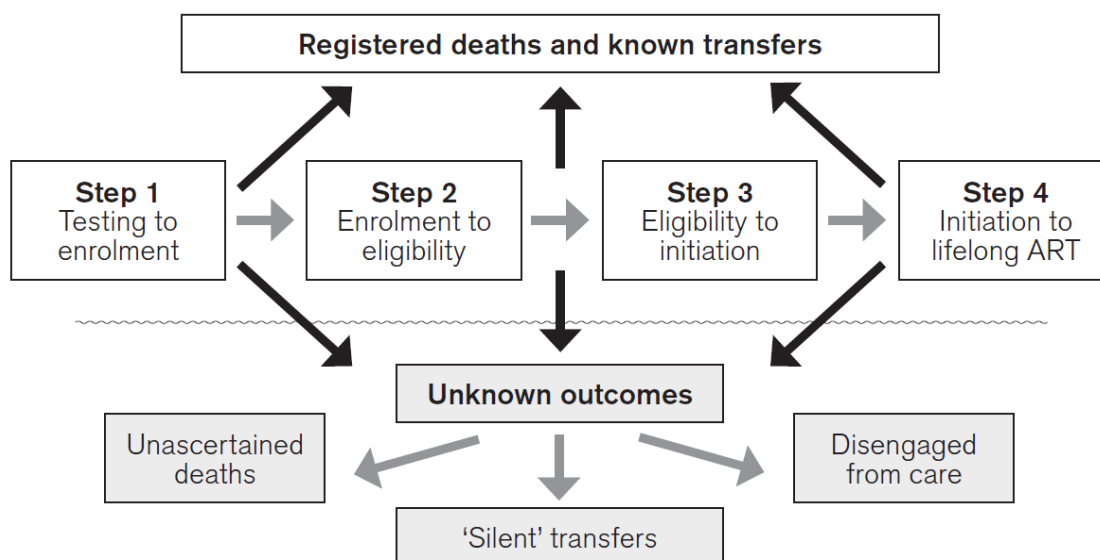
2.1 Introduction

The introduction of ART has helped mitigate the effects of the HIV/AIDS pandemic. Globally, by the end of 2011, over 8 million people had access to ART in low and middle-income countries (WHO, 2011).

NASCOP projected that by the end of December 2012, 620,000 Kenyans would be actively receiving life prolonging ART mainly through comprehensive care centers (NACC/NASCOP, 2011). Apart from being put on life prolonging ART, patients also receive continuous adherence counseling to ensure they consistently take their medication, psychosocial support and health education. These interventions offered in a comprehensive care clinic (CCC) set up are aimed at restoring and sustaining an individual's immune system.

2.2 Retention into Care

Retention in HIV care can be defined as continuous engagement from HIV diagnosis in a HIV clinic that offers a package of prevention, care, and treatment services. HIV care and treatment programs entail a continuum starting from diagnosis of HIV infection to initiation of ART and beyond. The continuum of care can be divided into four steps, thereby defining points at which patient attrition (the opposite of retention) occurs (WHO, 2011) as shown in Figure 1;



Step 1 – HIV testing to enrolment into care services

Step 2 – enrolment in care to ART eligibility (may be very short if person has WHO clinical stage 3 or 4 or a low CD4, or may be years for someone with a high CD4 count)

Step 3 – eligibility to initiation of ART

Step 4 – initiation to life long ART

Adopted from Baggaley R. Survey on Retention in HIV Care: A summary of findings

Figure 1 : The 4 steps along the continuum of HIV Care and Treatment.

HIV infected persons are lost at every step along the continuum of care, particularly in the period between HIV diagnosis and initiation of ART (Pre-ART period). Considerable attrition occurs during the preparation phase of ART, and program evaluations confined to on-treatment analysis significantly underestimate attrition (Zachariah *et al.*, 2011). A study conducted in Kenya showed that the risk of being lost to follow-up was particularly high before starting ART (Ochieng-Ooko *et al.*, 2010). Another study conducted in South Africa found that only 63% of people who tested HIV positive from clinical and voluntary counseling and testing centers were linked to initial HIV care (Kranzer *et al.*, 2010).

Retention in the ART period is better since LTFU rate is lower. A hospital based study on retention in care done in Malawi showed 6 month Retention rates of 4% for Pre-ART Patients vs. 90% for patients who started ART (Tayler-Smith *et al.*, 2010).

2.2.1 Importance of Retention

The need to ensure that HIV infected patients are retained in care is a public health issue and one that affects multiple populations (Horstmann *et al.*, 2009). With the increase in the number of people being enrolled to care, focus is now shifting to their retention into care. Retention emphasizes attending regularly scheduled clinic appointments and can be evaluated based on missed appointments and the percentage of patients who miss appointments over a specified period of time.

Despite the increasing accessibility to care and ART, retention to care has remained the major challenge in sub Saharan Africa (WHO, 2007). There has been a lot of focus mainly at those who have initiated ART (Rosen *et al.*, 2007) yet the Pre-ART patients are also an important group that should be retained in care to ensure optimal outcomes. Retaining patients in care in the pre-ART period is especially important as early initiation of ART reduces HIV-related mortality, can support women in the reproductive age group providing an opportunity to expand PMTCT coverage and partner involvement, and may have an impact on HIV transmission. Furthermore there is an opportunity to provide other clinical services in the 'pre-ART' period such as interventions to reduce morbidity and mortality for instance co-trimoxazole (CTX) prophylaxis and, isoniazid preventive therapy (IPT).

Emphasis on retention is driven by the knowledge that poor retention means poor adherence to medication leading to undesirable outcomes of increased mortality and

morbidity. Not retaining Pre-ART patients, means losing an opportunity to assess them for early initiation of ART, increased morbidity and mortality and missed opportunity for implementing prevention with positives interventions.

2.2.2 Retention Rates

Retention rates have been shown to vary widely across programs. Globally, the highest occurs within the first year of initiation of therapy. In 2010, the average global retention rate at 12 months was 81%, dropping to 75% at 24 months and to 67% at 60 months (WHO, 2011). A review of ART programs in sub-Saharan Africa revealed retention rates ranging from 24 percent to 77 percent after 2 years (Rosen *et al.*, 2007). Generally, ART programs in Africa have retention rates of 60% at the end of 2 years (Rosen *et al.*, 2007). Better patient tracing procedures, better understanding of lost to follow up (LTFU) and earlier initiation of ART to reduce mortality are needed if retention is to be improved.

2.2.3 Outcomes of Poor Retention

Poor retention is associated with the following adverse effects:

a) Decreased likelihood of receiving ART

Poor attendance of scheduled visits means patients will not be assessed for eligibility to initiating ART. This will lead to delay or lack of initiation of ART leading to high morbidity and mortality (Ullet *et al.*, 2009).

b) Antiretroviral treatment failure

Poor retention means higher chances of ART failure due to poor adherence to medication (Boden *et al.*, 1999). This in turn may lead to viral mutations that render existing drugs less

useful. Antiretroviral (ARV) drug failure means switching to more expensive second-line regimes.

c) Increased HIV transmission

In a study conducted in a clinic in Spain, wider availability of effective ART was associated with an 80% decrease in sexual transmission of HIV (Castilla *et al.*, 2005). Poor retention associated with poor adherence to ART means a high viral load and higher chances of onward transmission.

d) Increased hospitalization

Patients who drop out of care are likely to stop taking their medication. As a result increased viral replication leads to suppression of immunity and increased susceptibility to opportunistic infections and higher chances of hospital admission (Horstmann *et al.*, 2009)

e) Poor survival and even death

Inability to honor appointments means the patient will miss out on useful services offered, notably diagnosis and treatment of opportunistic infections. Poor adherence associated with LTFU means uncontrolled viral replication and immune suppression leading to the undesirable outcome of death (Horstmann *et al.*, 2009)

2.2.4 Factors affecting long term retention in care

Despite the positive attributes associated to it, retaining patients in care has remained a challenge in many ART programs. Several factors have been shown to affect retention to care ranging from patient factors to socio-cultural and health facility based factors.

Some of the factors affecting retention include:

i. Patient factors**a) Age**

Studies have associated younger age with poor retention (Ullet *et al.*, 2007). This might be due to the fact that the young, especially children and adolescents, depend on their more elderly parents for access to HIV care services. A study conducted in western Kenya associated younger age among other factors to LTFU (Ochieng-Ooko *et al.*, 2010) Another study conducted in Kenya and Malawi showed an association between young age <35 years, and attrition (Zachariah *et al.*, 2011).

b) Chronic comorbidity

Presence of chronic comorbidity was associated with better retention (Giordano *et al.*, 2007). However some comorbid conditions like tuberculosis have been shown to be responsible for early dropouts from care (in the first 6 months) leading to poor retention.

c) Gender

Female gender has been associated with better retention, while male gender has been associated with early loss to follow up (Zachariah *et al.*, 2011).

d) Education level

Post secondary education has been associated with better retention (Cherurat *et al.*, 2010). In a study conducted in Kenya to find out risk factors for LTFU, it was shown that a lower level of education is a risk factor for treatment denial and death, and thus LTFU (Karcher *et al.*, 2007).

e) Patient immune status at enrollment

A study conducted in Cameroon showed that patients with compromised immune status at enrollment were likely to be lost to follow up as were those who were TB HIV co infected

at enrollment (Tsague *et al.*,2005).Severe immune-suppression at enrollment may mean more likelihood of attrition due to death.

f) Disclosure status

Studies have shown that disclosure is associated with better retention (Cherurat *et al.* ,2010). Fear of disclosure and drug side effects might lead to non adherence and eventual loss to follow up (Weiser *et al.*, 2003).

g) Health status improvement

Health status Improvement was shown to be one of the major reasons why patients on care defaulted (McGuire *et al.*, 2010). With improved health, patients might resume activities which were incompatible with the frequency of hospital visits or might have decided to transfer to another health facility without notification (Tsague *et al.*,2005). One plausible explanation for poor retention would be the lack of incentive for asymptomatic individuals to return for monitoring.

h) The patients economic status

Poverty is a major cause of LTFU (Coleman *et al.*, 2007). This is because poor individuals might be unable to afford the costs of accessing health facilities. In programs where HIV care services are offered free of charge, the impact of hidden costs of accessing HIV care including transportation costs can lead to poor retention.

ii. Health care facility based factors

a) Distance to the health care facility

Patients coming from distant locations are likely to miss their appointments and subsequently become LTFU. A study conducted in Kenya showed that distance to healthcare facility independently predicts LTFU (Amin *et al.*, 2012). Another study found

an association between long travel time to the clinic with LTFU (Ochieng-ooko *et al.*, 2010).

b) Cost of services

Cheap or even free services are associated with higher retention rates. A retrospective analysis conducted at Mbagathi District Hospital in Kenya showed a difference in rates of LTFU between a cohort that paid 500 shillings per month (approximately US\$7) for ART and one that received medication free of charge. In the study, the overall risk reduction attributed to offering ART free of charge was 56.6 percent (95% CI 20.0-76.1). Payment for ART is associated with a significantly higher rate of LTFU, as some patients might be unable to sustain payment over time (Zachariah *et al.*, 2008).

c) Patient/provider relationships

Healthcare worker attitude and quality of services might impact negatively on retention. In a study conducted in Malawi, care dissatisfaction was noted as one of the main reasons for patients defaulting (McGuire *et al.*, 2010).

d) Organizational infrastructure of the health care facility visited

Integration of services has been shown to improve utilization and thus ensure retention. In a study to determine determinants to retention in urban Cameroon, difference in location of TB and HIV services might have contributed to the high proportion of loss to follow up (Tsague *et al.*, 2008).

iii. Community/Environmental factors

a) Social support system

Strong family and community support systems ensure the patient adheres to appointments. Treatment supporters will remind the patient to keep his/her appointments thus ensure they are retained to care. This support can be channeled through psychosocial support groups. Social support will contribute to reduced stigma which will go a long way in ensuring retention to care ((Horstmann *et al.*,2009).

b) Perceived HIV stigma within their communities

Stigma is a major hindrance to retention to care. A study in rural Tanzania revealed denial and doubts due to stigma as a major contributor to non-retention (Wringe *et al.*, 2009). A Malawian study recorded that stigma was one of the main reasons for defaulting (McGuire *et al.*, 2010).

c) Presence of patient tracing mechanisms

Availability of defaulter tracing mechanisms whether in the facility or community ensures those patients who miss their appointments are traced and helps ensure retention to care. Lower rates of loss to follow up have been reported in programs with patient tracing mechanisms (Stringer *et al.*, 2006) .A Kenyan study showed that an active defaulter tracing system is feasible in a resource poor setting and reduces LTFU among HIV, PMTCT, and TB patients(Thomson *et al.*,2011).

2.2.5 Strategies to Improve Retention

Strategies have been put in place to ensure retention to care but more needs to be done. These strategies can broadly be classified into those that reduce patient costs and those that increase patient benefits e.g. improving quality of services. WHO and UNAIDS in their new Treatment 2.0 strategy proposed 5 key elements that can help improve retention. These

include optimization of drug regimens, point of care diagnostics, reducing costs, adapting service delivery systems and mobilizing communities to engage and support PLHIV (WHO, 2011).

A study conducted in Kenya showed that frequent monitoring by dedicated nurses in the early months of ART can significantly reduce mortality and loss to follow up among high-risk patients initiating treatment in resource-constrained settings, thus improving retention (Braitstein *et al.*, 2012).

In summary, retention (remaining in care and on ART) in HIV care is essential to ensure long-term favorable clinical outcomes among HIV infected patients (Mannheimer *et al.*, 2005). Patients retained to care will have lower morbidity and mortality. Poor retention leads to undesirable treatment outcomes like drug resistance and death. Thus interventions need to be put in place to maximize retention to HIV care to ensure optimal outcome (Nachega *et al.*, 2010).

2.3 Conceptual Framework

This conceptual framework was developed after review of literature on factors affecting retention to care (Ochieng-ooko *et al.*, 2010, Zachariah *et al.*, 2011, Karcher *et al.*,2007, Tsague *et al.*, 2008, Massaquoi *et al.*.,2009).

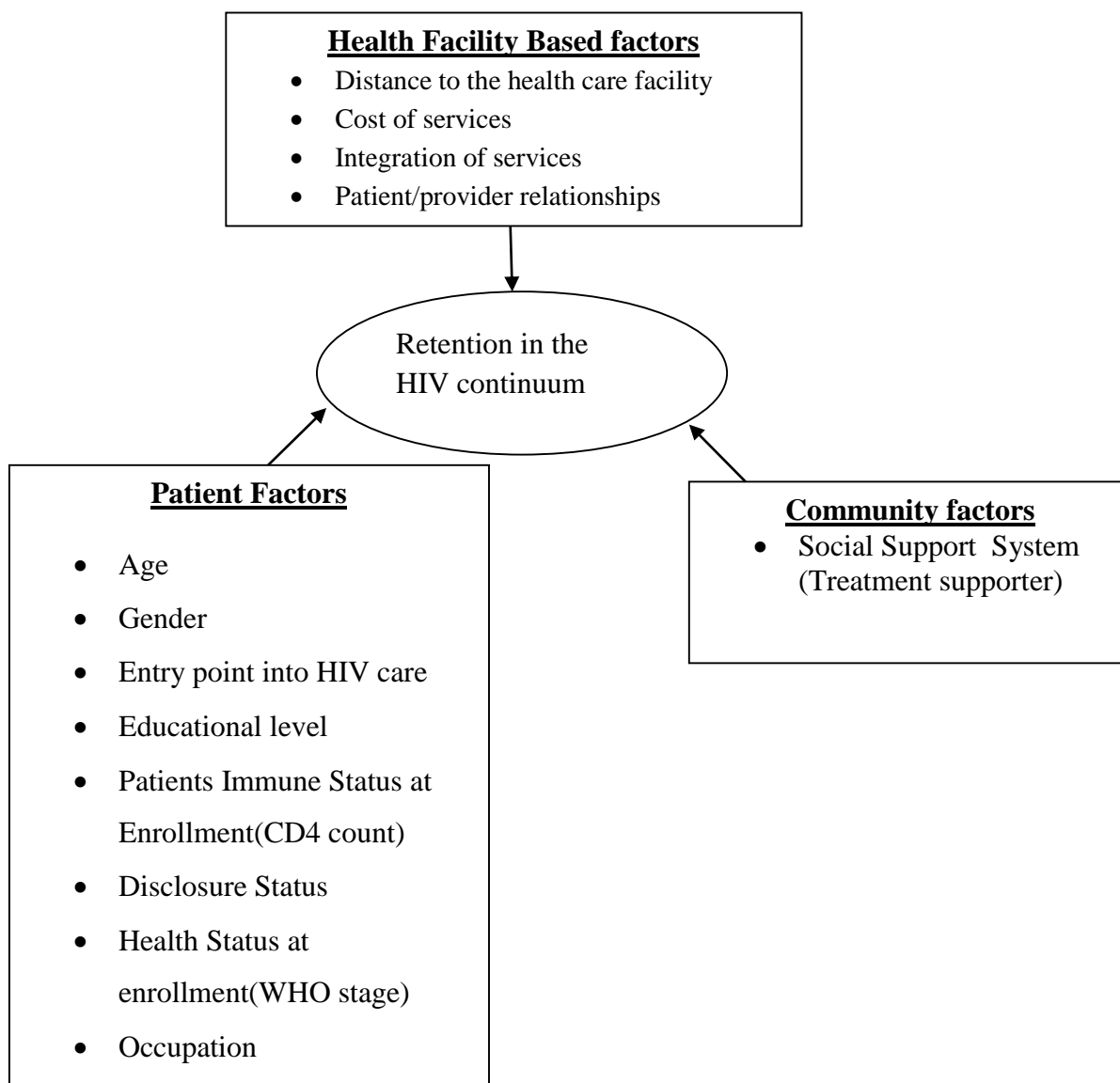


Figure 2 : Conceptual Framework of factors affecting long term retention to HIV care

CHAPTER THREE

METHODOLOGY

3.1 Study Area

The study was conducted in Siaya and Bondo County Hospitals in Siaya County. Siaya County is located in Nyanza and constitutes 5 sub-counties; Ugenya, Siaya, Gem, Bondo and Rarieda. Covering an area of 2,530 km² with a population of 842,304, the county ranks as the 20th largest in Kenya (Appendix A).

Siaya and Bondo County Hospitals are the two largest facilities in terms of work load in Siaya County with HIV services having commenced in both facilities in 2004.

By May 2012, the two facilities had enrolled the following number of HIV infected persons (DHIS, 2011);

Table 1: Cumulative number of clients enrolled in care and on ART

	Siaya County Hospital	Bondo County Hospital	Total
Current in care	9,172	7,715	16,887
Current on ART	5,145	3,374	8,519
Cumulative on ART	6,121	6,328	12,449

During the period in review, several strategies were in place at the two facilities to support retention of these patients in care. These were; adherence support, peer educators and a strong defaulter tracing system that entailed phone tracing and home visits.

These two facilities serve as the two main regional referral centers for other health facilities in Siaya County.

3.2 Study Design

This was a retrospective cohort study. The design entailed the use of existing medical records to assess characteristics of HIV infected adults (N=1,301) who were enrolled in HIV care in the period 1st January 2010 to 1st July 2010 at Siaya and Bondo hospital's Comprehensive care centers. This period was chosen so as to provide a follow-up period of more than 24 months for the cohort. Patients enrolled prior to this period were not included due to poor documentation of patient records (most patient records were incomplete). Documentation improved after January 2010 due to partner support that resulted in recruitment of additional staff that included health records information officers and data entry clerks.

3.3 Study Population

The study population was composed of records of HIV infected patients who were enrolled into HIV care between 1st January 2010 and 1st July 2010. The total number of adults enrolled at the two facilities in this period was 1,301 according to records.

3.4 Inclusion/Exclusion Criteria

To be eligible for the study, one had to be;

1. HIV positive
2. Above 13 years of age.

3. Enrolled into HIV care by registration in the pre-ART register within the study period (January 1, 2010 to July 1, 2010).

All HIV positive clients who did not meet the above criteria were excluded from the study.

3.5 Sample Size Determination

The sample size used in this study was derived from the Cochran formula enumerated as:

$$N = z^2_{\alpha/2} p(1-p)/d^2$$

Where n is the desired sample size, z is the z score at an alpha level of 0.05, alpha is the level of significance and d is the error tolerance level. The level of significance in this study was 0.05. As regards the proportion(p) that is patients likely to be retained after 2 years of follow up in an ART program; this study used 60% as evidenced by the different study results in sub-Saharan Africa (Rosen *et al.*, 2007).

Inputting the relevant values in the formula we therefore had;

$$N = (1.96)^2 (0.6) (0.4)/(0.05)^2 = 369$$

3.6 Sampling design

Stratified sampling was utilized in this study. The target population was divided into two strata, each comprising the district hospitals in the two districts – thus Siaya District Hospital and Bondo District Hospital. Systematic sampling was then used to access each patient record.

The table below represents the distribution of the target population:

Table 2: Target population distribution in Siaya and Bondo County hospitals

Hospital	Target population
Siaya County Hospital	690
Bondo County Hospital	611
Total	1301

Using proportionate allocation; $P = n/N$, where n is the number of patients in each district hospital and N is the size of the target population (1301) then we had the following proportions and sample from each district hospital. The sample size for each hospital was determined by multiplying the proportion by the target population.

Table 3: Proportionate allocation of Sample

Hospital	Proportion	Desired Sample Size
Siaya County Hospital	0.53	196
Bondo County Hospital	0.47	173
Total	1	369

Therefore, 196 and 173 records were to be reviewed from Siaya County Hospital and Bondo County Hospitals respectively. However, a total of 377 records were reviewed in this study, 200 from Siaya County hospital and 177 from Bondo County Hospital.

To enhance randomization, systematic sampling was applied. The sampling interval was determined by dividing the target population at each hospital by the desired sample size.

This is detailed in the table below:

Table 4: Systematic sampling

	N	N	K=N/n
Siaya County Hospital	690	196	4
Bondo County Hospital	611	173	4
Total	1301	369	

After sampling was done, every 4th record was checked for the variables of interest.

3.7 Study Variables

Dependent variable

Retention to chronic care_–This was divided into two categories; Retained in care if active and on follow-up at 24 months after enrolment and not retained if lost to follow up, transferred out or dead at the 24 month follow-up period.

Independent variables

Variables were chosen for the analysis based upon literature review either due to reported associations with retention in HIV treatment programs or postulated effect on retention.

Age – this variable was categorized into three sub-groups for the purposes of analysis; less than 21 years, 21-30 years, 31-40 years, 41-50years and more than 50 years.

Sex – there were two sex categories; male and female.

Education level_– education level was categorized as none, primary level, secondary level and college/university.

Entry point into HIV care – the service point in the health facility where the diagnosis of HIV is made was categorized as provider initiated counseling and testing (PITC), voluntary counseling and testing (VCT) home based counseling and testing (HBCT), outpatient department (OPD), inpatient department (IPD) and PMTCT.

Occupation-this was categorized into “employed” and “not employed”

Marital status_– this variable was categorized as single, married, cohabiting, separated, widowed or divorced.

Disclosure status at enrollment_– disclosure status was categorized as “disclosed” the patient has disclosed and “Not disclosed” if the patient had not disclosed.

Social support systems (treatment supporter) – this was categorized as “yes” if the patient had a treatment supporter and “No” if the patient lacked one.

WHO stage at enrollment_– there were four WHO categories; WHO stage 1, WHO stage 2, WHO stage 3 and WHO stage 4.

CD4 count at enrollment – This was categorized into 4 subgroups; CD4<200, CD4 count 201-400, CD4 count 401-600, CD4 count>600.

Distance to healthcare facility_– there were 4 categories for this variable; less than 5kms, 6-10kms, 11-20kms and more than 20 kms.

3.8 Data Collection Techniques,

Data was abstracted from medical records (pre ART register, EMR and patient files) at each site and sent to a data entry clerk after personal identifying information was removed. After quality control and verification, data were combined across sites to produce a uniform database. A data collection tool was administered for this purpose (Appendix B).

3.9 Data Processing and Analysis

Data collection and analysis were done in May 2013; this allowed for visits up to 24 months from date of enrollment into care. End time for all follow-up was July 1st 2012 for patients who were enrolled in care between 1st January and 1st July 2010. Medical records, (both electronic and manual registers) and individual patient files of the study participants were reviewed. Information was keyed in the data collection instrument (Appendix B). SPSS version 21 was used for all analyses.

Descriptive statistics were conducted to display the distribution of patient characteristics (independent variables) and overall retention in care. This analysis was stratified by sex to enable full understanding of retention patterns. After a general distribution was assessed, the independent variables were stratified by retention status. Chi-square test was performed to determine significant linear association between the independent variables and retention. Variables were deemed to have a significant association with retention if p-values were less than 0.05. These variables were then loaded into a multiple regression model which was used to calculate the risk of patients being retained in care with regards to independent

variables. The multivariate logistic regression analysis was run by forward selection to identify the variables that are associated with retention in care. The Kaplan-Meier survival curve was drawn to show the probability of patients remaining in care over a given length of time while considering time in many small intervals with the status of the patient (active or inactive) as at their last month of reporting. For each time interval, survival probability was calculated as the number of subjects surviving divided by the number of patients active. For each period, subjects who had died, dropped out, or moved out were not counted as “at risk”, subjects who are lost were considered “censored” and were not counted in the denominator. Total probability of survival till that time interval was calculated by multiplying all the probabilities of survival at all-time intervals preceding that time. This was used to compare survival for different categories for all the variables that displayed some level of significance in the Chi square test. These variables were; CD4 count at enrollment, marital status and WHO stage at enrollment. The results are presented using charts, text and tables.

3.10 Limitations

The study relied on accurate documentation on the registers and record keeping without which the findings might have been distorted. However to mitigate the impact of non documentation and incomplete records, the data source was not only limited to the registers but also included individual patient files. Incomplete files lacking key socio-demographics as age and gender, and clinical information as WHO stage were excluded from the analysis to reduce bias.

A key limitation of this study was non-definition of patients classified as lost to follow up (LTFU). It is not known whether this group of patients were actually dead, self transfer outs without formal documentation or they just 'de-registered' themselves. Secondly, in the analysis, patients that were transferred out (TO) during follow up were regarded as not retained. This is because this study was evaluating retention at facility level and this patients were not followed up to determine if they were still active and on care in the facilities where they were transferred to.

3.11 Ethical considerations

The following considerations were ensured;

- a) Permission to carry out the research study was sought from Moi University/Moi Teaching and Referral Hospital Institutional Research and Ethics Committee (Appendix C).
- b) Permission to access patient files and data was sort from the 2 hospital administrations (Appendix D and E).
- c) Confidentiality was guaranteed by not indicating the names of the study subjects on the data collection tool. The potential breach in patient confidentiality during data retrieval by research assistants was addressed by ensuring the health records officer extracted data to be used by the research assistants in such a way that the names were excluded. This ensured that the research assistants only handled de-identified data. Secondly, the study engaged clinical officers working at the study sites as research assistants who are bound by confidentiality regulations.

CHAPTER FOUR

RESULTS

4.1 Baseline characteristics

4.1.1 Sociodemographic characteristics

Data was collected from 377 patient records in two HIV clinics in Siaya County; Bondo and Siaya County hospitals in May 2013. Two hundred and forty five (65%) of the patients were females; their mean age was 35.1 years (range 14-91); Women were younger than men (mean 34.1 and 37.1 respectively). Most of the patients (76%) lived within a distance of less than 10 km from the hospital of enrollment.

At enrollment, 14% of the patients had never been married; 63.2% were either married or cohabiting; 15.6% were widowed while 7.3% were divorced or separated. Eighty one percent of the patients who were married were in a monogamous relationship while 18.8% were in polygamous relationships.

At enrollment to care, 4.8% of the patients had not attended any formal education; 59.4% had attained primary level education; 20.7% had attained secondary education and 5.6% had attained college or university education. Education level for 9.5% of the patients was not indicated.

4.1.2 Patient immune status at enrolment

One hundred and seventy two patients (46%) had CD4 cell counts below 200/uL at enrollment. Those enrolled with CD4 cell counts between 201 and 400/uL were 160 (42%) while 26 (7%) were enrolled with CD4 cell counts between 401 and 600/uL. The rest, 19

(5%) had CD4 cell counts more than 600. The median CD4 absolute count at enrollment into care was 220 cells/mm³ (Range 1-1366).

4.1.3 WHO stage at enrollment

Less than half of the patients, 172(46.5%) were enrolled at WHO stage 3 while 68(18%) were enrolled at WHO stage 1, those enrolled at WHO stage 2 were 118(32%) and 12(3.2%) were enrolled at WHO stage 4.

4.1.4 Entry point into care

The entry point into care for 50% of the patients was provider initiated counseling and testing (PITC). Voluntary counseling and testing (VCT) contributed 37.4% of the patients enrolled into care while home based counseling and testing (HBCT) accounted for 12.6% of the patients.

4.1.5 Disclosure of HIV status at enrollment

Regarding disclosure of HIV status at enrolment into care, 81.8% of the patients had disclosed their HIV status to either a relative or a spouse while 18.2% had. More men (83.5%) had disclosed their HIV status compared to women (75.6%).

Table 5: Baseline characteristics of the patients both overall and stratified by gender

Measure	Overall	Male	Female	p Value
Mean age (SD)	35.1 (11.23)	37.1 (10.0)	34.1 (11.7)	0.487
CD4 count Mean, (SD)	238.6 (198.1)	211.3(177.8)	253.2 (207.0)	0.002
Median CD4 counts (Range)	220 (1366)	206 (1058)	227(1366)	
WHO stage				
WHO I <i>n</i> (%)	68 (18.4)	11 (16.2)	57 (83.8)	0.010
WHO II <i>n</i> (%)	118 (31.9)	40 (33.9)	79 (66.1)	
WHO III <i>n</i> (%)	172 (46.5)	70 (40.7)	103 (59.3)	
WHO IV <i>n</i> (%)	12 (3.2)	8 (66.7)	4 (33.3)	

4.2 Long term retention to care

4.2.1 Retention rates at 24 months

After 24 months of follow up after enrollment into HIV care, 220 (58.4%) of the patients were still active in care. Sixty one (16.2%) of the patients had transferred out to other facilities. The rest either died (2.7%) or were lost to follow-up (22.8%). Considering the transfer-outs as retained, the retention rate after 24 months of follow up was 74.6%. However, since this study was estimating retention at facility level, excluding transfer outs from the 'retained' leads to retention rates of 58.4%.

Fifty eight percent of patients enrolled at Bondo County hospital were active in care after 24 months of follow up, the rest were either transferred out (12%), lost to follow up (26%) or dead (5%). While for those enrolled at Siaya County hospital, 59% were active in care at 24 month follow up period, 20% were transferred out, 20% were lost to follow up and 1% died.

Among the 377 patients sampled, fifty eight percent of female patients were retained in care at 24 months; 18% of female patients were transferred out, 23% of female patients were classified as lost to follow up and 1% were classified as dead. Among male patients, 58% were retained, 13% were transferred out, 23% were lost to follow-up and 6% died.

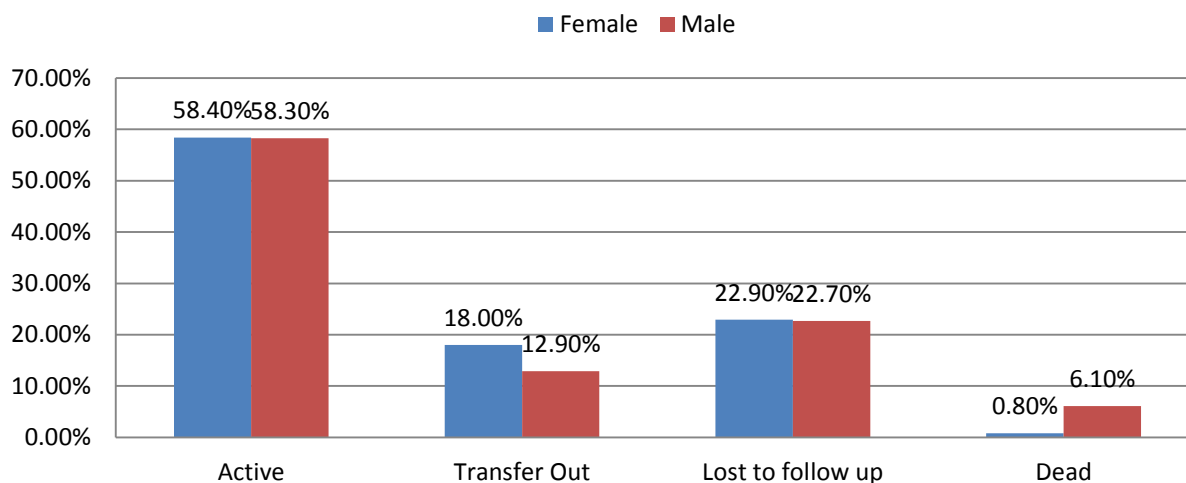


Figure 3 : Bar graph showing outcomes at 24 months stratified by gender

4.2.2 Factors affecting long term retention to care

4.2.2.1 Bivariate analysis

Detailed analyses of factors associated with long-term retention to care are shown in Table 6. Seventy five percent of patients whose CD4 levels were above 600 were retained in care at 24 months. Patients with CD4 counts 401- 600/uL at enrolment had 87.5% of them active in care at 24 months while the rest (12.5%) were either transferred out or lost to follow up. Among patients with CD4 counts 201- 400 at enrolment, 64% were active in care at 24 months while the rest (36%) were either dead, lost to follow up or transferred out. Among patients with a CD4 count value less than 200 at enrolment, 48% were active in care at 24 months while the rest (52%) transferred out, were lost to follow or died. CD4 cell count at enrolment was found to have a significant association with retention ($p=0.001$).

Seventy two percent of patients enrolled at WHO stage 1 were retained while 28 percent were either LTFU dead or transferred out at 24 months. For patients enrolled at WHO stage

2, sixty one percent were active while 39% were inactive at 24 months. For those enrolled at WHO stage 3, fifty three percent were active at 24 months of follow-up while 47% were inactive. Finally for patients enrolled at WHO stage 4, forty two percent were active at 24 months of follow-up while fifty eight percent were inactive. WHO stage at enrollment was found to be significantly associated with long term retention to care ($P=0.031$).

Thirty nine percent of patients, whose marital status at enrollment was single, were active in care at the 24 month follow-up period. Sixty two percent of these patients were either lost to follow up, transferred out or dead at 24 months. Sixty three percent of patients, whose marital status at enrollment was married, were active in care at the 24 month follow-up period. Thirty seven percent of these patients were not active at this period. Patients who were separated at enrollment had 64% of them active in care at 24 months while 37% of them were inactive at this time period. Thirty eight and sixty one percent of those divorced and widowed at enrollment respectively were active at 24 months. Finally, 75% of the patients whose marital status was cohabiting were retained in care at 24 months of follow up. Marital status at enrollment was found to have a statistically significant association with retention at 24 months ($p = 0.024$).

Patients who were employed at enrollment had 60 percent retained in care at the 24 month follow up period. Forty percent were either dead, lost to follow up or transferred out at this time period. For those who were not employed at enrollment, 65% were active at the 24 month follow-up period while the rest (35%) were either dead, lost to follow up or transferred out at the same period. Occupation status at enrollment into care was found to have a statistically significant association with retention ($p=0.030$).

The other patients factors analyzed showed no difference between the two groups. There was no significant variation in retention of patients in care at 24 months with regards to Sex ($p=0.970$), age at enrollment ($p=0.0553$) entry point into care ($p= 0.839$), education level at enrolment ($p=0.587$), having a treatment supporter at enrollment ($p=0.118$) and disclosure of HIV status at enrollment ($p=0.448$).

Table 6: Patient characteristics stratified by retention status at 24 months

Characteristics		Status at 24 months of follow-up			
		Active n (%)	Inactive (LTFU, Dead, TO) n (%)	Total	p value
Sex	Male	77(58.3)	55(41.7)	132	0.970
	Female	144(58.5)	102(41.5)	246	
Age	<21	12(60)	8(40)	20	0.553
	21-30	109(57.7)	80(42.3)	189	
	31-40	59(54.1)	50(45.9)	109	
	41-50	34(68)	16(32)	50	
	>50	6(66.7)	3(33.3)	9	
Marital status	Single	20(38.5)	32(61.5)	52	0.024
	Married	144(63.4)	83(36.6)	227	
	Separated	7(63.6)	4(36.4)	11	
	Divorced	6(37.5)	10(62.5)	16	
	Widowed	36(61.0)	23(39)	59	
	Cohabiting	3(75)	1(25)	4	
	Not indicated	5(55.6)	4(44.4)	9	
Education level	None	12(63.2)	7(36.8)	19	0.587
	Primary	131(58.2)	94(41.8)	225	
	Secondary	41(52.6)	37(47.4)	78	
	University/College	14(70)	6(30)	20	
	Not indicated	23(63.9)	13(36.1)	36	
CD4 cell count at enrollment	<200	82(47.7)	90(52.3)	172	0.001
	201-400	103(63.6)	59(36.4)	162	
	401-600	21(87.5)	3(12.5)	24	
	>600	15(75)	5(25)	20	
WHO stage at enrollment	1	49(72.1)	19(27.9)	68	0.031
	2	72(61)	46(39)	118	
	3	92(53.2)	81(46.8)	173	
	4	5(41.7)	7(58.3)	12	
Disclosure of HIV status	Disclosed	176(59.5)	120(40.5)	296	0.448
	Not disclosed	35(52.2)	32(47.8)	67	
	Not indicated	10(66.7)	5(33.3)	15	
Occupation status at enrollment	Employed	176(59.5)	120(40.5)	296	0.030
	Not employed	35(64.8)	19(35.2)	54	
	Not indicated	10(35.7)	18(64.3)	28	
Treatment supporter	Yes	194(60.4)	127(39.6)	321	0.118
	No	24(50)	24(50)	48	
	Not indicated	3(33.3)	6(66.7)	9	
Entry point into HIV care	VCT	77(58.3)	55(41.7)	132	0.839
	OPD	61(55)	50(45)	111	
	IPD	13(52)	12(48)	25	
	PMTCT	25(64.1)	14(35.9)	39	
	HBCT	23(54.8)	19(45.2)	42	

4.2.2.2 Multivariate analysis

In multivariate analysis (Table 7), a patient enrolling to care with higher CD4 count was more likely to be retained in care for 24 months than a patient enrolling in HIV care with lower CD4 count who was more likely to transfer out, get lost to follow-up or be dead at 24 months of follow-up. Adjusting for WHO stage, occupation and marital status, a patient enrolling to care with CD4 counts less than 200 had 70% decreased likelihood of being retained in care as compared to a patient with CD4 more than 600($p=0.03$). On the other hand, a patient enrolled to care with CD4 cell count 201- 400 had a 40% decreased likelihood of being retained to care as compared to a patient enrolled with CD4 cell counts more than 600($p=0.32$). A patient enrolled to care with CD4 cell counts 401- 600 was twice more likely to be retained to care ($p=0.29$).

A patient enrolling at an advanced WHO stage was less likely to be retained to care for 24 months after enrollment. Adjusting for CD4 cell count, occupation and marital status at enrollment, a patient enrolled at WHO stage 1 had 3 times increased likelihood of being retained in care for 24 months as compared to a patient with WHO stage 4($p=0.04$). Similarly, a patient enrolled at WHO stage 2 had twice increased likelihood of being retained in care for 24 months ($p=0.20$). Whereas a patient enrolled at WHO stage 3 had 1.5 increased risk of being retained in care for 24 months ($p=0.44$).

In this study, patients who were in any form of employment were less likely to be retained to care as compared to patients who were not in any form of employment. Being employed conferred a 20% decreased likelihood of being retained in care ($p=0.56$).

Table 7: Multivariate logistic regression for factors associated with retention

Variable	Crude OR (95% CI)	Adjusted Odds ratio(95% CI)	P Value
WHO stage 1	3.943(1.033-15.043)	3.611 (1.020, 12.779)	0.04
WHO Stage 2	2.247(0.631-7.996)	2.191(0.656, 7.318)	0.20
WHO Stage 3	1.672(0.479-5.829)	1.590 (0.486, 5.205)	0.44
WHO Stage 4	1	1	
CD4 (below 200)	0.204(0.062-0.676)	0.304(0.0106-0.873)	0.03
CD4 (201-400)	0.359 (0.107-1.201)	0.582(0.201-1.682)	0.32
CD4 (401- 600)	2.652(0.390-18.013)	2.333(0.482-11.297)	0.29
Over 600	1	1	
Single	0.153(0.014-1.669)	0.208 (0.020-2.144)	0.19
Married	0.466(0.046-4.773)	0.578(0.059-5.650)	0.64
Separated	0.823(0.056-12.011)	0.583(0.044- 7.661)	0.68
Divorced	0.191(0.015-2.471)	0.200(0.017-3.286)	0.20
Widowed	0.405(0.038-4.3338)	0.522(0.051-5.324)	0.58
Cohabiting	1	1	
Employed yes	0.705(0.364-1.366)	0.838 (0.462-1.522)	0.56
Employed No	1	1	

The Kaplan Meier survival estimate was generated to estimate the overall probability of a patient being retained in care after enrolling. The survival curve below shows the overall probability of remaining in care for the patients:

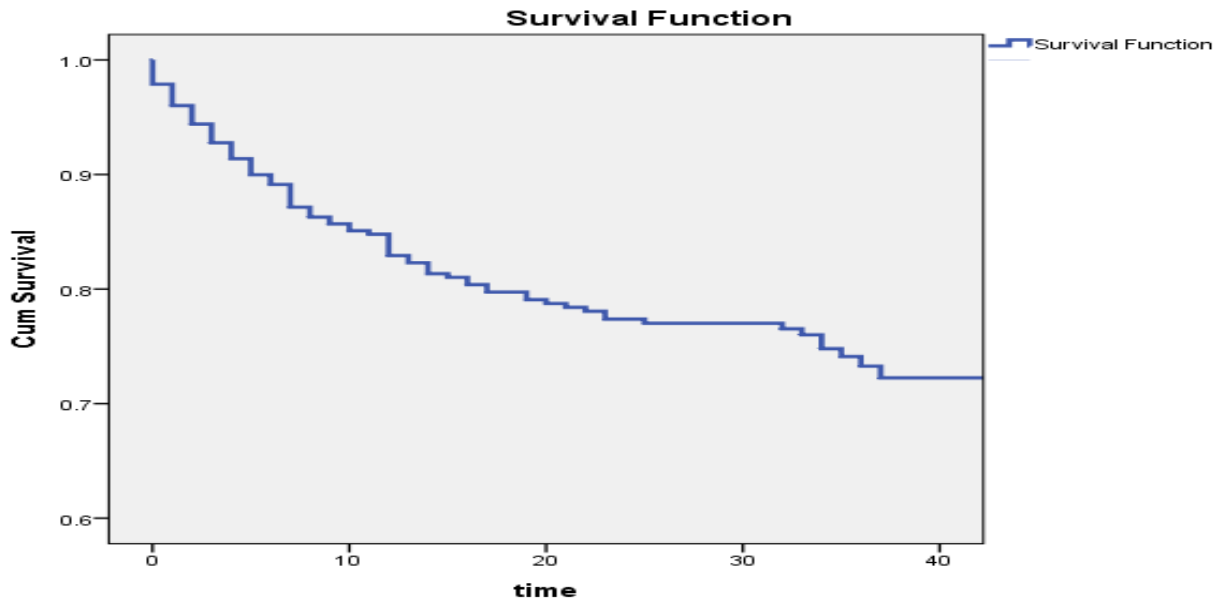


Figure 4 : Survival analysis on retention to care

Kaplan-Meier curves (figure 6) show that patients with WHO stage 4 at enrolment ($p=0.000$) had an increased probability of not remaining in care.

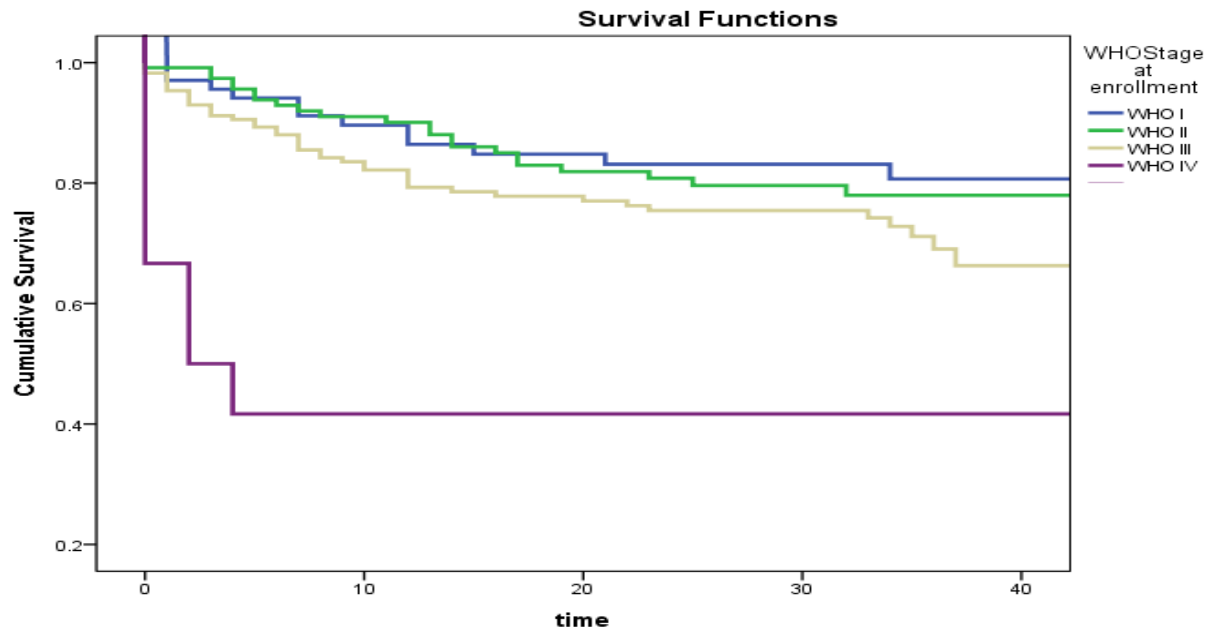


Figure 5 : Kaplan Meier probability of remaining in care by WHO stage at enrollment.

A comparison of the patient retention by the point of enrollment into care and sex was also done (figure 7 and 8) and indicated no significant difference in their survival at 95% confidence interval ($p\text{-value} > 0.05$).

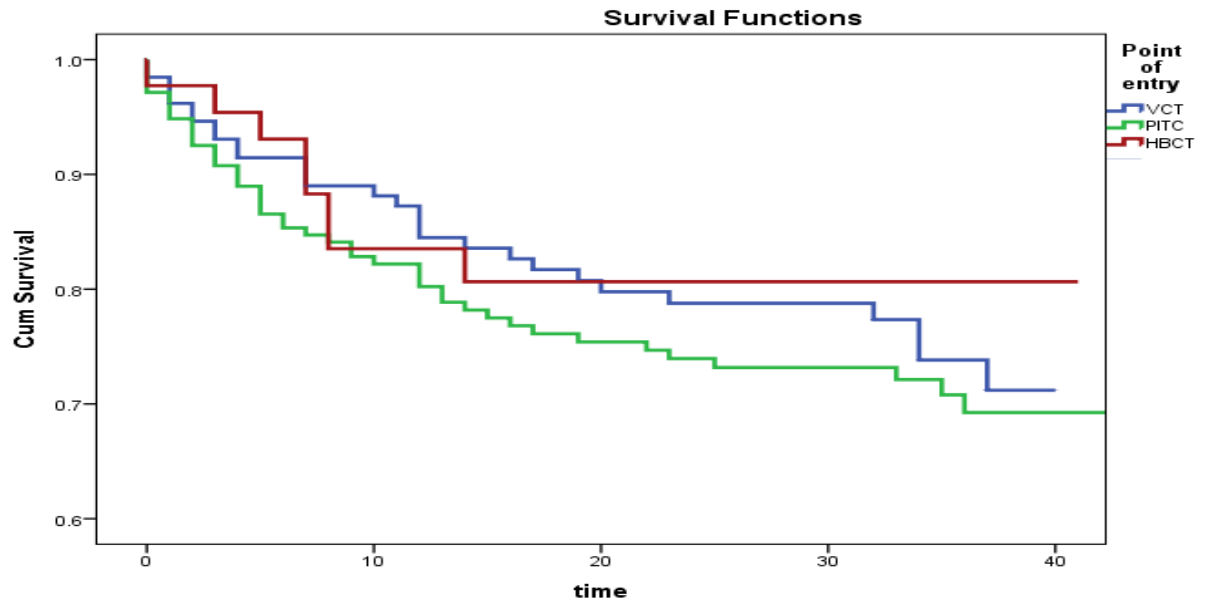


Figure 6 : Kaplan Meier probability of remaining in care by entry point into HIV care

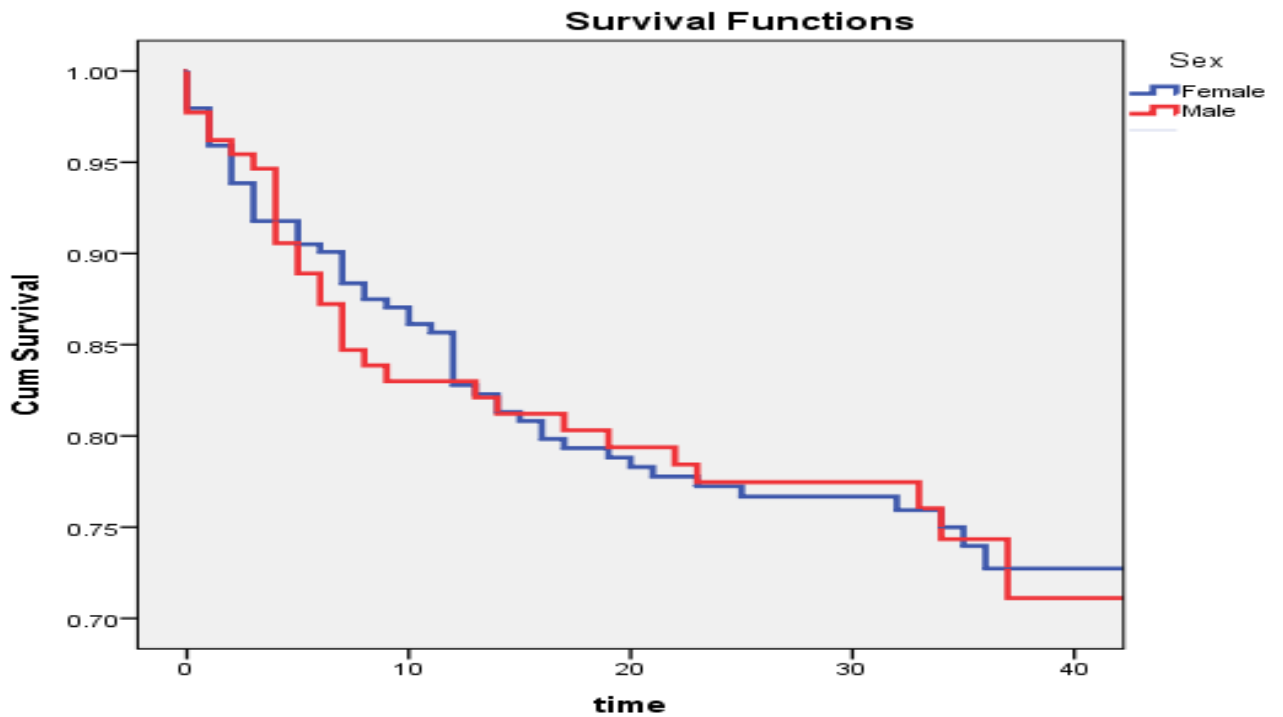


Figure 7 : Kaplan Meier probability of remaining in care by sex

CHAPTER FIVE

DISCUSSION

5.1 Long term retention in care

Retention in long-term HIV care both before and after the initiation of ART is important not only to reduce individual HIV-related mortality and morbidity but also as a means to deliver "positive prevention" interventions aimed at reducing ongoing transmission. Fifty eight percent of the patients were still active and on care at the two facilities after 24 months of follow up. The main reason for disengagement from care was loss to follow up (22.8%), 16.2% transferred out to other facilities and 2.7% died during the follow up period. Retained patients have been defined as "patients known to be alive and on follow up at the end of a follow up period" (Rosen *et al.*, 2007). Using this definition, the retention rate at 24 months in this two facilities was 58.4%. Other authors have proposed retention in care to include those patients formally transferred out to other facilities (Massaquoi *et al.*, 2009, Cheever *et al.*, 2007). Taking this definition into account, the retention rate for this setting is 74.4%. However, we need to interpret this retention rate with caution since we are not certain whether the transfer outs were still active and on follow up in the facilities to which they transferred to. These findings are relatively consistent with findings from other HIV programs in Africa that have shown retention rates ranging from 24 percent to 77 percent after 2 years (Rosen *et al.*, 2007). This finding also compares with the 2010 WHO estimation of the average global retention rate at 24 months of 75% (WHO, 2011). The lost to follow up rate in this setting was unacceptably high especially considering the fact that these two hospitals had in place an active defaulter tracing mechanism that entailed both

phone and home visits of patients who missed their appointments. A study by Stringer *et al.*, 2006 reported lower rates of loss to follow up in programs with patient tracing mechanisms. This thus calls for the need to evaluate the effectiveness of the defaulter tracing strategies in place. Undocumented transfers may have accounted for a large proportion of patients LTFU especially in the context of rapid decentralization of HIV services that occurred in Siaya County during the follow up period. It has been shown that in decentralized settings like Siaya county where HIV services have been decentralized to the lower level facilities, 25-50% of patients who are deemed to be lost to follow up may actually be retained in care elsewhere (Geng *et al.*, 2010).

5.2 Factors affecting long term retention in care

In this study, long term retention was affected by the following patient factors; WHO stage at enrolment, CD4 count at enrolment, occupation status at enrolment and marital status. WHO stage 1 disease at enrolment was independently associated with increased likelihood of retention while CD4 < 200/uL was independently associated with decreased likelihood of retention. Patient factors such as entry point to care, disclosure of HIV status and education level were not shown to be significant in this study as was reported by Cherurat *et al.*, 2010, Zachariah *et al.*, 2011, Amin *et al.*, 2012. This study found that distance to health facility was not significantly associated with retention. This is contrary to findings by Ochieng-ooko *et al.*, 2010 and Amin *et al.*, 2012 that found an association between long travel time to the clinic with LTFU. This finding from this study may be attributed to decentralization of HIV care to lower level facilities that occurred in Siaya county that addressed access challenges occasioned by distance. In this setting, majority of patients lived within a distance of less than 10 km from the hospital of enrollment.

Patients enrolled at Siaya DH were more likely to be retained for 24 months compared to those enrolled at Bondo DH. This difference in retention could be due to specific health facility based factors that have an impact on retention. There is need to assess the health facility specific factors that could have contributed to this difference in retention.

Patients presenting with early disease stage were more likely to be retained to care for 24 months after enrollment as compared to patients presenting with advanced disease stage. These findings compare positively with findings from other studies that have shown worse retention for patients presenting with advanced HIV disease stage and those with opportunistic infections (Ochieng-ooko *et al.* ,2010, Zachariah *et al.* ,2011, Tayler-Smith *et al.*, 2011). The relatively poor retention of patients enrolled to care with advanced disease stage in this study might be due to the fact that these patients might have died as a result of opportunistic infections or they were just too sick and therefore not able to keep their appointments. Secondly, since Siaya and Bondo DHs are the two largest facilities that serve as referral hospitals in the region, the very sick patients would have just visited for treatment of opportunistic infections some as inpatients and upon discharge or recovery, they may have self transferred to continue care at other facilities. Targeted interventions, including aggressive identification and treatment of opportunistic infections for patients presenting with advanced disease stage, may improve both retention in care and clinical outcomes.

Related to the patient clinical status, immune status at enrollment may be a significant determinant of retention to long term HIV care. Patients with higher CD4 count were more likely to be retained in care for 24 months after enrollment. Patients enrolled with CD4

counts less than 200 were shown to have poor retention at 24 months. These findings are in agreement with findings from other studies that have shown that patients with compromised immune status at enrollment were likely to be lost to follow up (Tsague *et al.*, 2005). Brown *et al.*, 2006). A study conducted in Cameroon by Tsague *et al.*, 2005 for instance showed that HIV patients enrolled with severe immunosuppression, and those co-infected with TB were more likely to be lost to follow-up early and thus had poor retention to care. However a study conducted in western Kenya showed poor retention in patients with baseline CD4 > 200 (Ochieng-ooko *et al.*, 2010). Other studies have demonstrated a bidirectional association between CD4 count and probability of retention whereby both low and higher CD4 counts have both been associated with worse retention (Geng *et al.*, 2010, Zannou *et al.*, 2008). The poor retention among patients with lower CD4 counts in this study may have been due to the fact that these patients were too sick to continue on care, or may have died. The other reason could be that upon improvement of their CD4 levels and thus health status, these patients felt no need to continue care or might have resumed activities which were incompatible with the frequency of hospital visits or might have decided to transfer to another health facility without notification (Tsague *et al.*, 2005).

Social factors have been found to be important determinants of retention in a number of settings (Frank *et al.*, 2008, Wringe *et al.*, 2009, McGuire *et al.*, 2010). In this study, a patient who was married/cohabiting, widowed or divorced at enrollment into HIV care was likely to be retained in care for 24 months of follow up as compared to an unmarried one ($p=0.024$). The high likelihood of retention among those who are married or cohabiting could be due to social support and the accompanying social expectations that help overcome barriers to care. A study conducted in Kenya associated being single with higher rates of

LTFU (Amin *et al.*, 2012). Siaya and Bondo DH support a family model of care whereby appointments are scheduled with families in mind. This could among other things be promoting appointment keeping and thus retention especially among the married/cohabiting patients.

Disclosure of HIV status at enrollment, a marker of social support did not affect retention in care. A study conducted earlier showed that disclosure is associated with better retention (Cherurat *et al.*,2010) and that fear of disclosure and drug side effects might lead to non adherence and eventual loss to follow up (Weiser *et al.*, 2003). Findings from this study are also contrary to findings from a study by Ochieng-ooko *et al.*,2010 that showed that individuals who disclosed their HIV+ status before enrolment were less likely to be lost to follow up. Majority of the patients in this study (82%) had disclosed their HIV status to their relatives or sexual partners at enrolment. A study by Antelman *et al.*,2001 showed that disclosure rates start from as low as 5.8% at enrolment to care and increase over time. Furthermore, in this study, more males than females had disclosed their HIV status at enrollment, findings that are contrary to Deribe *et al.*,2009 who showed higher rates of disclosure in females than males. The high rate of disclosure of HIV status at enrolment in this study might be as a result of sustained health education and evidence of a community that has finally been ‘destigmatised’ and has accepted to discuss and confront HIV . Over the years, a lot of resources have been channeled to health education to fight stigma in a region where HIV was once a taboo subject. However, further research is needed to assess the factors that influenced the very high disclosure rates at enrollment and the gender differences in this setting.

Occupation status at enrolment, a proxy of socioeconomic status seems to significantly determine retention in care. Patients who were in some form of employment were less likely to be retained in care as compared to patients who had no employment. This finding contradicts findings that have shown poverty as a major cause of LTFU (Coleman *et al*, 2007). Reasons for this finding need to be evaluated further but could be down to the fact that in the study set up most patients who were employed actually engaged in blue collar jobs that may not have guaranteed them enough income to take care of all their needs including health care needs. Secondly, a significant number of patients were self employed as fishermen and this can affect their retention to care, due to their migratory nature. The employed patients might also have been unable to keep their appointments due to work commitments. Scheduling clinic hours targeting the employed patients including during weekends would make it easier for those who work to attend and thus ensure they are retained to care.

This study had several challenges. First, the data was collected retrospectively from patient records in a context of routine care and hence chances of underreporting of events. Secondly, this being a retrospective study from two hospitals in Siaya County, the findings may not be generalizable to other settings, however the analysis may provide insights applicable to other settings. Non definition of LTFU was a major limitation in this study. As a result, it is not known whether this group of patients were actually dead, self transfer outs without formal documentation or they just 'de-registered' themselves.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

The following conclusions are drawn from this study;

Half of the patients were retained to care after 24 months of follow up. This retention rate was low and was comparable to the WHO estimate of global retention rates and the 2 year retention rates for ART programs in sub Saharan Africa. Lost to follow up was the main cause of attrition. Definition of lost to follow up patients might have an effect on retention rates since some of them might have died; self transferred or just 'deregistered' themselves from care. This can be achieved through a review of the existing defaulter tracking strategies to make them more efficient. A significant proportion of patients were transferred out to decentralized health facilities. Information systems that capture patient details at a regional level for instance at county level are essential to capture outcomes of such patients who are transferred out. A small proportion of patients were lost through death. To ensure optimal outcomes from HIV care and treatment, strategies have to be put in place to retain more patients to care. These strategies should target factors that have been shown to affect retention to care.

Factors affecting long term retention to care were; baseline CD4 count, WHO stage at enrollment, marital status, and occupation. WHO stage 1 disease at enrollment was independently associated with better retention to care while CD4 cell count less than 200 at enrollment was independently associated with poor retention to care. This finding shows that patients enrolled at advanced disease stage and low baseline CD4 count were more likely not to be retained to care. Enrolment at advanced disease stage and low baseline CD4

count is associated with lower retention in care as a result of early mortality and loss to follow-up. The significance of this finding is that enacting strategies to promote early testing for HIV and linkage to care will lead to a reduction in mortality and lost to follow up and thus improve long term retention to care.

The following factors were found not to affect long term retention to care: Patient factors (age, sex, education level, disclosure of HIV status, entry point into HIV care), health facility based factors (distance to health facility) and community/environmental factors (having a treatment supporter).

Findings from this study can be used to inform policy to improve the retention in long term HIV care in Kenya at facility level by targeting the patients at higher risk of not being retained to care.

The following recommendations at facility level will help improve long term retention of HIV positive patients to care;

- i. Early diagnosis of HIV before deterioration of immune and clinical status and linkage to care. This will be achieved through integrating routine opt out HIV testing in all hospital departments and home based counseling and testing. Linkage of all the patients testing positive to care should be ensured. This can be achieved by promoting same day enrollment. Those opting to be enrolled to other facilities other than where the test was performed should have their tracer information documented for follow up to ascertain linkage.
- ii. Facilities also need to give more support to those patients enrolling at advanced disease stage (WHO stage 4 and CD4 <200). This can be achieved by strategies

targeting this group of patients like more frequent clinic appointments, aggressive screening and treatment of opportunistic infections, forming special psychosocial support groups for this group of patients and engaging peer patients to support retention.

- iii. Defaulter tracing mechanisms should also be strengthened at facility level to be able to track and account for all patients who miss appointments. All patients classified as lost to follow up should be tracked and their real status determined and documented. A follow up should be made to ensure that patients who were transferred out actually reached the destination facilities and continued with care. A review of the existing defaulter tracing mechanisms should also be carried out to determine their effectiveness.
- iv. Finally, better health information systems that will ensure accurate documentation in the relevant records so that all patients are accounted for. This will ensure easy identification of any patients that are lost to care.

At policy level, the following recommendations will help improve long term retention to care;

- i. Enforce already existing guidelines for early diagnosis of HIV to support diagnosis and enrolment into care. Despite having guidelines promoting voluntary routine opt out HIV testing, there is need to support implementation of these guidelines especially in the non-medical settings.

- ii. Develop and implement a package of care for patients enrolling at advanced immunological and clinical status clearly highlighting the interventions to ensure they are retained to care.
- iii. Policies to ensure adequate funding of HIVcare especially to support management of opportunistic infections and defaulter tracing. This is especially critical in the context of dwindling donor support. The county governments need to allocate resources to support the above interventions to ensure patients are retained in care.
- iv. Enact policies to guarantee adequate well trained workforce to absorb influx of patients. This can be achieved partly by making it attractive for HCW to work in rural settings like Siaya so as to address the regional variations in the workforce.

Areas for further research include assessment of the effectiveness of defaulter tracing systems. This is due to the fact that despite the presence of a robust defaulter tracing mechanism in this setup, lost to follow up rates were high. Secondly, research to better understand patients lost to follow up would go a long way in improving retention. This can be achieved by sampling based approaches that can be used track a numerically small but representative sample of patients with unknown outcomes. Research to understand how health facility based factors affect retention to care is necessary. This retrospective study could only assess distance to health facility since data on the other possible health facility based factors that affect retention is not routinely collected.

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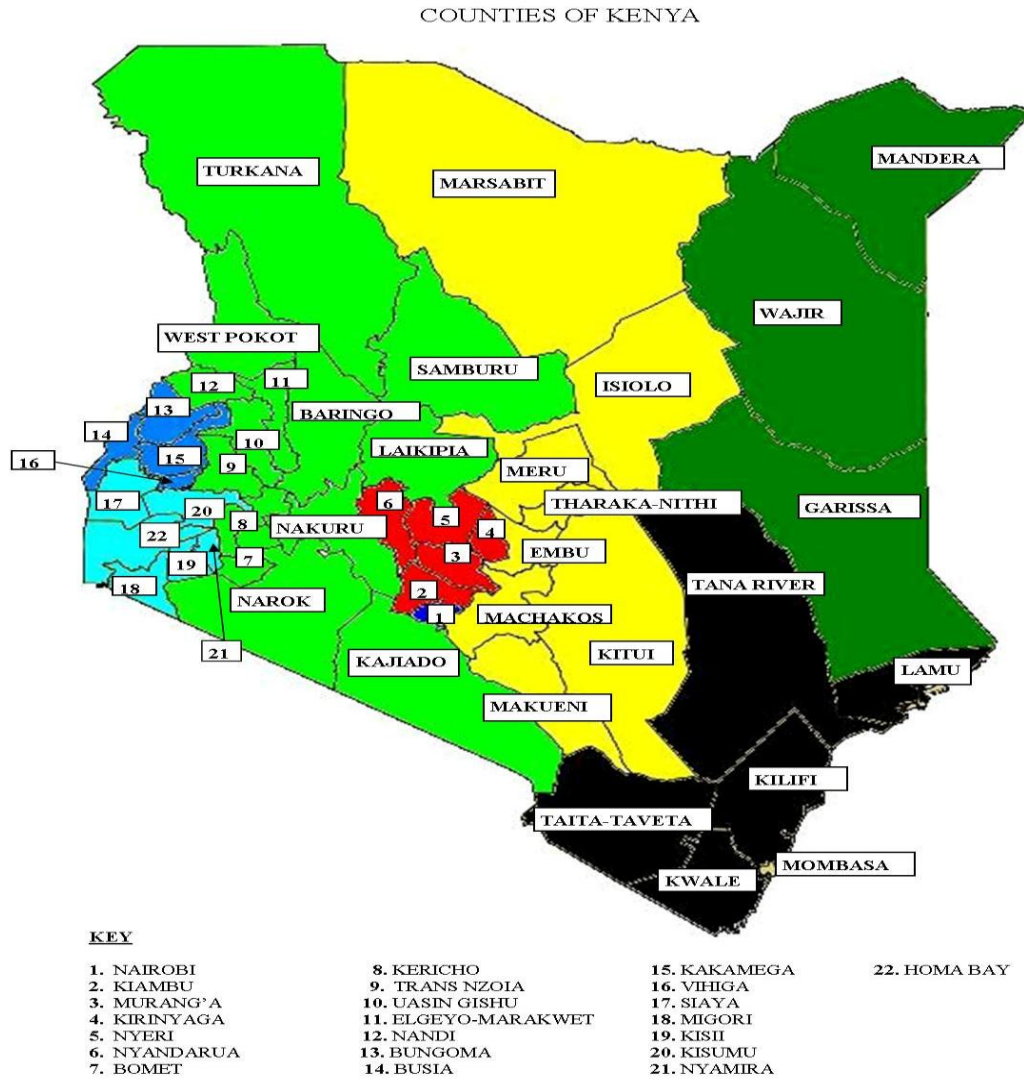
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APPENDICES

Appendix A: Map of Kenya showing Siaya County



Appendix B: Data Collection Form

APPENDICES

Appendix 1: Data Collection Form

Patient unique number	Age	Sex(M/F)	Occupation	Marital status	Baseline CD4	WHO stage at enrollment	Treatment supporter	Distance to health facility	Entry point to HIV care



Appendix C: Moi University/MTRH IREC Approval Letter



MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471/2/3

INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)



MOI UNIVERSITY
SCHOOL OF MEDICINE
P.O. BOX 4906
ELDORET
Tel: 33471/2/3
27th June, 2013

Reference: IREC/2013/53
Approval Number: 0001012

Jacquin Kataka,
Moi University,
School of Public Health,
P.O. Box 4606-30100,
ELDORET-KENYA.

Dear Ms. Kataka,

RE: FORMAL APPROVAL



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

“Factors Affecting Long Term Retention of Adult Patients to Chronic HIV Care in Siaya and Bondo District Hospitals.”

Your proposal has been granted a Formal Approval Number: **FAN: IREC 1012** on 27th June, 2013. You are therefore permitted to begin your investigations.

Note that this approval is for 1 year; it will thus expire on 26th June, 2014. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

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

Sincerely,

W. Aruasa
DR. W. ARUASA
VICE-CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

cc: Director - MTRH
Principal - CHS
Dean - SOM
Dean - SPH
Dean - SON
Dean - SOD

Appendix D: Permission to carry out study in Siaya DH

MINISTRY OF HEALTH

Telegram: "MEDICAL , Siaya
Telephone: Siaya 057-321031
E-mail Siayamoh@yahoo.com
When replying please quote
Ref. No.SYA/MOH/VOL II/207
6



SIAYA COUNTY REFERRAL HOSPITAL
SIAYA DISTRICT HOSPITAL
P.O. BOX 144
SIAYA.

15th JULY 2013

DR. JACQUIN KATAKA
P.O. BOX 17681 – 00100
NAIROBI, KENYA

Dear Doctor,

RE: RESEARCH AUTHORIZATION

Following your application to carry out research for your MPh thesis on “Factors Affecting Long Term Retention of Adult Patients To Chronic HIV Care in Siaya and Bondo District Hospitals”, I am pleased to inform you that you have been authorized to undertake research in Siaya County Referral Hospital.

The following suggestions were made about your thesis proposal:

- Change the name of the hospital from Siaya District Hospital to Siaya County Referral Hospital
- Use the Vancouver system in referencing the studies and papers you have quoted as the recommended system in use today for thesis and studies
- Include a table showing the timeframe for your study including dates for ethical approval, enrolment, data analysis and results feedback
- In Ethical considerations, please include that permission will also be sought from the hospitals involved in the study namely Siaya County Referral Hospital and Bondo District Hospital

On completion of the research, you are expected to submit a soft and hard copy of the results to the hospital IRC.

Sincerely,

DR. JAMES WAGUDE
CHAIRPERSON, INSTITUTIONAL REVIEW COMMITTEE
SIAYA COUNTY REFERRAL HOSPITAL

cc

Medical Superintendent – Siaya County Referral Hospital

Appendix E: Permission to carry out study in Bondo DH

REPUBLIC OF KENYA



MINISTRY OF HEALTH

Bondo District Hospital
Tel: +254-723616241
P.O. Box 595-40601
BONDO
bondodistricthospital@gmail.com
Date: 15th June 2013

When replying Please quote:

Our Ref:

Your Ref:.....

DR. Jacquine Kataka
P.O BOX 17681 – 00100
Nairobi Kenya

Dear Dr. Kataka,

RE: RESEARCH AUTHORIZATION

This is to notify you that your application to conduct the research study “Factors Affecting Long Term Retention of Adult Patients to Chronic HIV Care in Siaya and Bondo District Hospital” has been granted by the management of Bondo District Hospital effective 25th June 2013.

Please note the following;

- (i) Notify us of any changes in the study protocol.
- (ii) Upon completion of your study, share your findings with the hospital management team.

Sincerely

A handwritten signature in black ink, appearing to read 'Felix Tindi', written over a horizontal line.

Dr. Felix Tindi

Felix
The Medical Superintendent, Bondo District Hospital

Appendix F: Work Plan

Activity	Year 1 (2012)				Year 2 (2013)			
	Q1 (Jan to Mar)	Q2 (Apr to June)	Q3 (July to Sept)	Q4 (Oct to Dec)	Q1 (Jan to Mar)	Q2 (Apr to June)	Q3 (July to Sept)	Q4 (Oct to Dec)
Proposal Writing								
Ethical review								
Piloting data collection tool								
Data collection analysis and report writing								
Proposal defense								
Dissemination/publication								

Appendix G: Budget

Budget Item	Cost
Research Assistant allowance (2 research assistants)	Ksh 20000
Paper for printing data collection tool	Ksh 2 000
Printing data collection tool	Kshs 2000
Total	Ksh 24 000