

**FACTORS ASSOCIATED WITH RETENTION IN CARE
AMONG HIV POSITIVE ADULTS ATTENDING PUMWANI
COMPREHENSIVE CARE CENTRE, IN NAIROBI COUNTY,
KENYA**

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2018

**Factors associated with retention in care among HIV positive
adults attending Pumwani comprehensive care Centre, in
Nairobi County, Kenya**

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**A thesis submitted in partial fulfillment for the degree of Master
of Science in public health in the Jomo Kenyatta University of
agriculture and technology**

2018

DECLARATION

This thesis is my original work and has not been presented for a degree in any other University.

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DEDICATION

To my parents Joseph and Alice Ronoh who taught me perseverance and hard work, as virtues to uphold. These virtues enabled me to achieve this work.

ACKNOWLEDGEMENTS

Almighty God for granting me all the resources to attend this course and bringing me this far. Indeed your grace has been sufficient.

My supervisors: Professor Peter Mwaniki, Dr. Joseph Mutai and Dr. Mutisya A. Kyalo for their availability, tireless guidance and prompt assistance during the entire period of the study.

I am greatly indebted to the senior management of Pumwani Maternity Hospital and the entire staff who gave me the opportunity and support to conduct the study in the Clinic. Special mention goes to Sophie Mwasi and Lucy Magothe, who supported me with data collection. Analyses of the results would not have been finally completed without the assistance of Richard Gichuki and Charity Muthoni. Thank you for your valuable work.

Sincere thanks to my mentor Dr Simon Njenga for his endless time and constant support at all stages, for his guidance and encouragement me all the way through the study.

Last but by no means the least, the respondents for voluntarily participating without which there would be no study to thank all the others above for.

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ABBREVIATIONS AND ACRONYMS

AIDs	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CCC	Comprehensive Care Centre
CDC	Center for Disease Control
CD4	Cluster of Differentiation four
FGD	Focus group discussion
HCW	Health Care Worker
HIV	Human immunodeficiency virus
ICAP	International Center for AIDS Care and Treatment
KAIS	Kenya AIDS Indicator Survey
LTFU	Loss to follow-up
MoH	Ministry of Health
NACC	National Aids Control Council
NASCOP	National Aids and STI control Program
PITC	Provider Initiated Testing and counseling
PLHIV	People Living with Human Immunodeficiency Virus

PMH	Pumwani Maternity Hospital
SSA	Sub Saharan Africa
UNAIDS	United Nations Program on HIV/AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

OPERATIONAL DEFINITION OF TERMS

- Access:** proportion of those on ART among all HIV-infected eligible adults and adolescents who were aware of their HIV status
- Adherence:** How faithfully a person sticks to and participates in his or her HIV prevention, care, and treatment plan
- Anti-retroviral therapy:** combination of drugs to maximally suppress the HIV and stop the progression of HIV disease. The standard treatment consists of a combination of at least three drugs (often called “highly active antiretroviral therapy” or HAART) that suppress HIV replication
- Anti-retroviral therapy period:** Time in which a client is on drugs that suppresses the HIV and stop the progression of HIV
- Attrition:** discontinuation from care for any reason, including death, loss to follow-up, and stopping ARVs medications while remaining in care, transfer to another HIV care facility
- Coverage:** proportion of those on ART among all HIV-infected eligible adults and adolescents, irrespective of knowledge of HIV status
- Comprehensive Care Centre:** is a clinic where people living with HIV go for holistic care and management.
- Defaulters:** A patient is classified as a defaulter if they are more than 7 days, but less than or equal to 90 days, late to their expected appointment.
- Engagement in care:** embodies the distinct but interrelated process of linkage and retention in care

Enrollment: Entry into care after HIV diagnosis, defined as a visit with HIV care provider authorized to prescribe ART

HIV: Human Immunodeficiency Virus

HIV cascade/continuum: sequential steps a client undergoes from HIV testing to Viral load suppression.

Linkage: Linkage to care is the process of engaging newly diagnosed HIV-infected persons into HIV primary care

Loss to follow up: A patient is classified as lost to follow up if they have not been to the HIV care center for more than 90 days since their last appointment date.

Missed appointment: A patient is classified as having a missed appointment if they are more than 3 days, but less than or equal to 7 days, late to their expected appointment.

Pre-antiretroviral therapy: time when a client is not yet on ART but accessing other services

Quarterly visit: A medical appointment that is comprehensive which includes; clinician appointments, clinical and lab monitoring, psychosocial support, treatment of any infections and refill of ARVs

Retention in care: Attending required provider visits for primary HIV care and having attended a minimum of 2 visits in last six months.

Transfer out: movement of a client from care from one site to another

Viral load: quantitative measure of HIV virus particles in a milliliter of one's blood. These particles are called copies.

Visit:

Contact with health care worker at a health facility.

ABSTRACT

Despite the benefits of antiretroviral therapy for persons with human immunodeficiency virus, various obstacles contribute to poor engagement in HIV care, substantially limiting the effectiveness of efforts to improve health outcomes for those with HIV and to reduce new HIV transmissions. A cross-sectional descriptive study design employing quantitative and qualitative data collection was used to determine factors associated with retention in care among HIV-positive adults in Pumwani comprehensive care Centre located in Kamukunji Sub County in Nairobi County. Data collection tools were structured questionnaire and focus group discussion. Systematic sampling was used to get a sample size of 350 participants (aged 18 years and above) and purposive sampling used in selecting 18 participants in the focus group. Data was analyzed using SPSS software and descriptive statistics generated. In addition, chi square test and logistic regression analysis were used to determine the factors associated with retention in HIV care. Notes from the focus group discussions were transcribed, translated, coded, analyzed thematically and presented in verbatim. The study received ethical approval from Kenyatta National Hospital/University of Nairobi ethical review committee. Participants signed an informed consent. Findings show that proportion of retention in care was at 66.8% with 73.5% being female. Of those retained, 70.3% were aware testing occurs at a health care provider point and 75% knew they were to be linked successfully within 3 months of diagnosis, while 70.7% knew they were to see a health provider at least four times in a year. Those who knew that HIV diagnosis could be diagnosed by a health provider were two times likely to be retained (OR 2.057, $p=0.028$), while if one is on ARVs they have four times chance of being retained (OR 3.994, $p< 0.001$). Participants in the focus group agreed that most clients discontinued care during the pre-ART period and competing life activities affected attendance of scheduled appointment. This study concludes that despite free access to ART services, retention in care is still a challenge. Competing life activities affects attendance to scheduled clinic appointments, while being on ARVS and testing done by a health provider are facilitators of retention in care. This

study recommends adoption of community model for ART distribution, to lower chances of missed appointments and supports all HIV infected individuals to be on ARVS.

CHAPTER ONE

INTRODUCTION

1.1 Background

HIV has presented huge challenges universally and Kenya is among the countries most affected by the epidemic. Significant scale up of HIV/AIDS services has been done in the past decade, especially in sub-Saharan Africa (SSA) where the epidemic is home to an estimated 25 million people representing around two-thirds of the people living with HIV globally (UNAIDS, 2014). In Kenya HIV prevalence is at 5.6% with 60.5% of those eligible taking antiretroviral therapy (ART). This means that close to 40% of HIV-infected persons in need of ART were not receiving it at the time of the survey. Among those aware of their HIV infection and eligible for ART, coverage of ART was 84.5%. Still, 15.5% of persons who were aware of their infection and in need of ART were not receiving it (KAIS, 2012).

In spite of the roll out of HIV services and scale up of ART in SSA, various challenges have emerged with the scale up of HIV/AIDS programs at different levels of service provision. The success of these programs has considerably been affected by high levels of attrition across the HIV care continuum. Lost to follow up (LTFU) is the common cause of attrition in HIV programs accounting for up to 59%, followed by death at 41% (Fox & Rosen, 2010).

Retention in HIV care starts from initial engagement in care, when a person with HIV is linked successfully to services, to assessment for eligibility, initiation of ART and retention in lifelong ART care. Poor retention of patients in care, especially in the pre-ART period is a key driver of poor performance and increased morbidity and mortality in HIV/AIDS program (Fox & Rosen, 2010). Linkage to care after testing positive is not enough as one needs to be retained in care in order to fully benefit from HIV services provided (Bofill, Waldrop-Valverde, Metsch, Pereyra, & Kolber, 2011).

Retention is significant in reducing HIV-related morbidity and mortality, incidence of new infections, and development of ART resistance. It provides additional benefits through ancillary services, social support, and secondary prevention messages that can help patients navigate a lifelong and complex infection (NASCO, 2011). All these efforts lead to marked decrease of HIV transmission thereby stemming the HIV epidemic. And the maximum benefits of ART is derived when PLHIV after early diagnosis are linked and retained in care (Cohen et al., 2011).

Researchers and health care providers agree that timely linkage to and engagement in medical care is a matter of priority for individuals who are HIV infected (Mayer, 2011); since HIV infection is an incurable illness that requires long-term engagement with health-care providers ((Bofill et al., 2011). Regular follow ups, good adherence and retention in care leads to successful outcomes. Appointments at HIV Comprehensive Care Centre (CCC) in Kenya are scheduled to correspond with prescription refills, adherence support, and timely delivery of required interventions. Clinic attendance is a proxy for retention in care (NASCO, 2011). Repeatedly missing appointments have been shown to lead to non-adherence to medication, faster disease progression, and treatment failure (Alamo et al., 2012; Fong, Cheng, Vujovic, & Hoy, 2013).

Some of the factors that have been associated with LTFU which affects retention rate include: younger age, male sex, loss after one visit, unknown partner HIV status and lack of disclosure (Alamo et al., 2012; Stolka et al., 2016). An understanding of challenges that affect retention in HIV care, will help to develop strategies that will improve retention in care amongst HIV infected individuals. The objective of this study was to identify factors associated with retention in care amongst HIV positive clients as they continuously engage in HIV care and treatment in Pumwani CCC in Nairobi County.

1.2 Statement of the problem

Poor retention in care has a potential negative impact on outcomes of ART programs. (Geng et al., 2010) highlight that the extent and the factors associated with retention vary substantially and encourage studies in different settings to inform programmatic decisions. The need to retain People living with HIV (PLHIV) is a pressing public health issue and one that affects multiple populations. New HIV infections are projected to come from people who live with the virus, know their HIV status and not enrolled in care services or lost to follow up from the service. Maintaining these clients in care has potential impact not only in reducing AIDS related mortality but also preventing new infections (Cohen et al., 2011).

Retaining PLHIV in medical care after diagnosis is essential in initiating lifesaving antiretroviral therapy and facilitate the delivery of important prevention messages for reducing HIV transmission (NASCO, 2011). Retention in care is critical for HIV care continuum as attrition leads to poor outcomes; clinically, immunologically and virologically leading to increase of HIV transmission and this undermines prevention efforts. Maximizing retention may require both medical and socio-behavioral strategies after an understanding of those factors associated with retention in HIV care.

1.3 Justification of the study

Although many HIV positive patients have benefited with ART, still some patients do not continue with follow-up visit for treatment schedules (Geng et al., 2010). This has led to Programme gaps in fully attaining its goal of no death due to HIV/AIDS. Reasons as to why HIV positive patients who are linked successfully begin care and put on treatment fail to continue with follow up visits still is a question most programs are unable to answer (WHO, 2011). Retention of HIV positive patients in care, treatment and good adherence are vital determinants of achieving long term positive outcomes both for the individual and programs.

Success of PLHIV being retained in HIV/AIDS programs requires an understanding of factors that influence retention because clients who are poorly retained in care cause an interruption to care and this has an effect on client's health and on global fight of HIV.

This study provides valuable insights on factors associated with retention in care among PLHIV and an important step in understanding and reinforcing strategies that will help a client continuously to be engaged and retained in care. The findings will assist the national government (through the Ministry of Health and NASCOP), Nairobi County government and Pumwani Maternity Hospital comprehensive care Centre to improve the services with a view to making them more relevant to the needs of persons living with HIV.

It is a significant step towards understanding HIV care systems and factors a patient faces as they engage in care. It is also valuable to guide the improvement of patient centred HIV care programs ultimately improving retention.

1.4 Research Questions

- i.** What is the proportion of retention in care among HIV positive clients attending Pumwani comprehensive care Centre?
- ii.** What is the knowledge and perceptions of HIV positive adults attending Pumwani comprehensive care Centre regarding retention in care?
- iii.** What factors are associated with retention in care among HIV positive adults attending Pumwani comprehensive care Centre?

1.5 Objectives

1.5.1 Broad Objective

To determine factors associated with retention in care among HIV positive adults attending Pumwani comprehensive care Centre in Kamukunji Sub County in Nairobi County.

1.5.2 Specific Objectives

- 1) To determine proportion of retention in care among HIV positive adults attending Pumwani comprehensive care Centre
- 2) To establish knowledge and perceptions of retention in care among HIV positive adults attending Pumwani comprehensive care Centre
- 3) To determine factors associated with retention in care among HIV positive adults attending Pumwani comprehensive care Centre

1.6 Conceptual framework

The conceptual framework for this study identified factors such as: Personal characteristics, social economic, psychosocial factors such as; denial and stigma and health service factors such as appointment waiting time that directly and indirectly affects adherence and retention in care. The study aimed to identify factors and quantify their contribution towards retention in care.

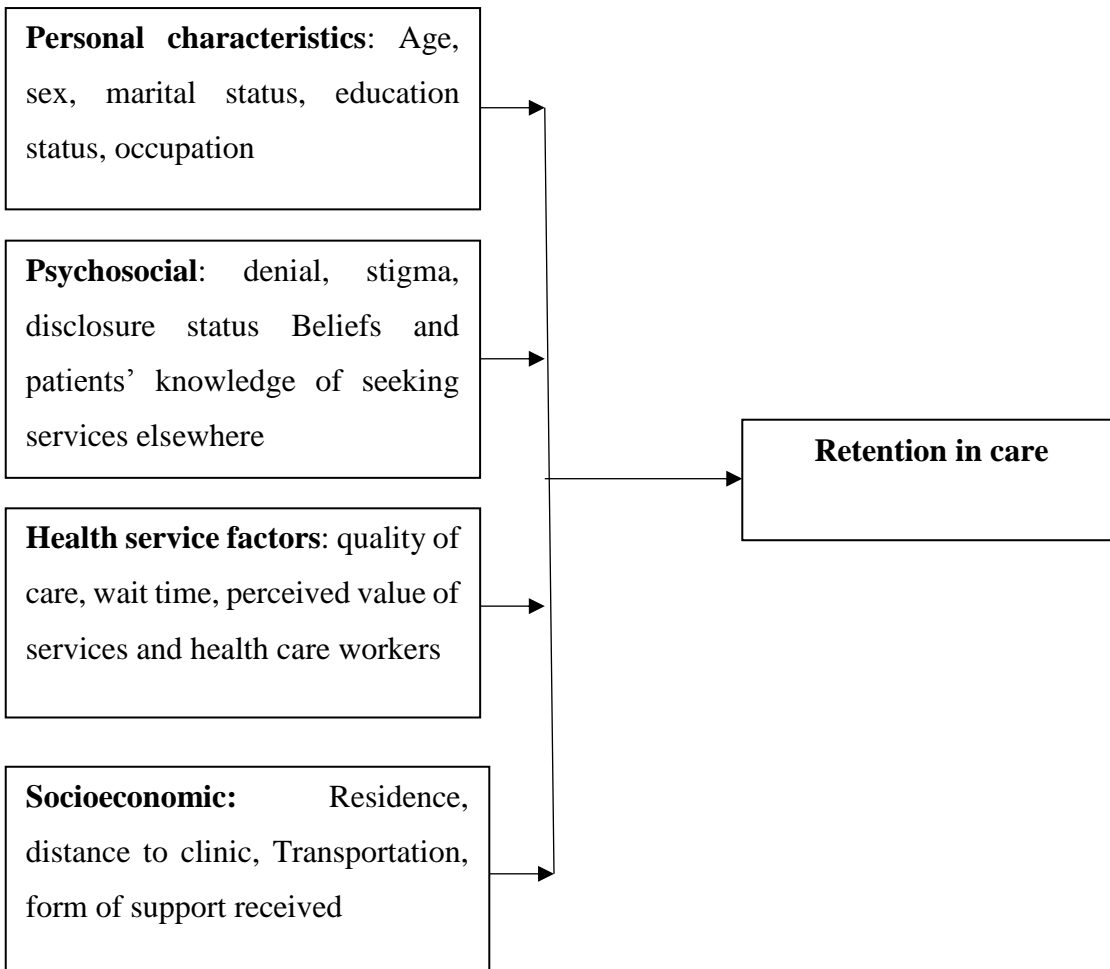


Figure 1.1: Various concepts associated with retention in HIV care

CHAPTER TWO

LITERATURE REVIEW

2.1 Epidemiology of HIV/AIDs

Since the start of the epidemic, almost 71 million people have been infected with the HIV virus and about 34 million people have died of HIV. Globally, 36.9 million people were living with HIV at the end of 2014 with an estimated 0.8% of adults aged 15–49 years worldwide living with HIV. However, the burden of the epidemic continues to vary considerably between countries and regions. Sub Saharan Africa (SSA) remains most severely affected, with nearly 1 in every 20 adults (4.8%) living with HIV and accounting for nearly 70% of the people living with HIV worldwide (UNAIDS, 2015).

Southern and eastern Africa bears the greatest burden of HIV in the SSA region. Kenya alongside Mozambique and Uganda has the largest number of PLHIV with 1.6 million HIV infected in 2013. Roughly 58,000 people died from AIDS-related illnesses in the same year although this dropped by 32% between 2009 and 2013 (UNAIDS, 2014). HIV prevalence peaked at 10.5% in 1996, and had fallen to 5.6% by 2013 primarily due to the rapid scaling up of ART. The first case of HIV in Kenya was reported in 1984, and by the mid-1990s it was one of the major causes of mortality in the country placing enormous demands on the healthcare system as well as the economy (KAIS, 2012), and has remained to be a major public health problem affecting people of productive age group. HIV related deaths have significantly reduced over the years due to the increase of number of people accessing treatment and 740,000 PLHIV were on ART up from 630,000 patients in 2013 (CDC Kenya, 2015).

HIV continues to be a major challenge across all the 47 Counties in Kenya. However, it is noted that some Counties have a considerably higher HIV burden than others, and among them Nairobi has the highest number of PLHIV at 177,552 and HIV prevalence at 8% (NAS COP, 2011). As recommendations to test and treat all individuals diagnosed with

HIV is further scaled up, the need to retain PLHIV in care is becoming more significant. UNAIDS (2014) report targets of 90 90 90; requires that 90% to be tested and linked to care if found to be HIV positive, 90% is put on ART and 90% be virally suppressed. And all this is tenable when a client is retained in care.

2.2 HIV care continuum and patient retention in care

Retention in HIV care is defined as continuous engagement from the time of diagnosis in a package of prevention, treatment, support and care services (WHO, 2011). HIV continuum of care has sequential steps of HIV medical care in which the HIV infected person accesses services at each stage for the purposes of prevention and psychosocial support. It begins with HIV testing and diagnosis, linkage to and retention in medical care; getting ART and achieving viral suppression (CDC Kenya, 2014).

The HIV care continuum begins with a diagnosis of HIV infection. People who don't know they are infected are not accessing the care and treatment they need to stay healthy and can unknowingly pass the virus on to others. After a diagnosis of HIV infection, it is important to be connected to a healthcare provider who offers treatment and prevention counseling to help one stay as healthy as possible and prevent passing HIV on to others. Because there is no cure for HIV at this time, treatment is a lifelong process. To stay healthy, one requires regular HIV medical care. Treatment with ART can help people with HIV live longer, healthier lives, and has been shown to reduce sexual transmission of HIV by 96 percent when they are virally suppressed (CDC Kenya, 2014).

The HIV cascade is a universal model used in engagement in care research that outlines critical elements for successful treatment of HIV-infected persons. Particularly it depicts timely diagnosis, linkage to care, retention in care, initiation of ART and achievement of an undetectable viral load (Gardner, McLees, Steiner, Del Rio, & Burman, 2011). In past years a tremendous amount of research has been dedicated to medication adherence, the focus on successful linkage, engagement and retention in medical care within the HIV community has been relatively limited. Thus far, researchers have directed their studies

toward the specific stages portrayed on the spectrum of engagement, focusing on linkage, retention, and/or reengagement in care, in addition to barriers to care. However, a patient's location on the continuum of care is not static.

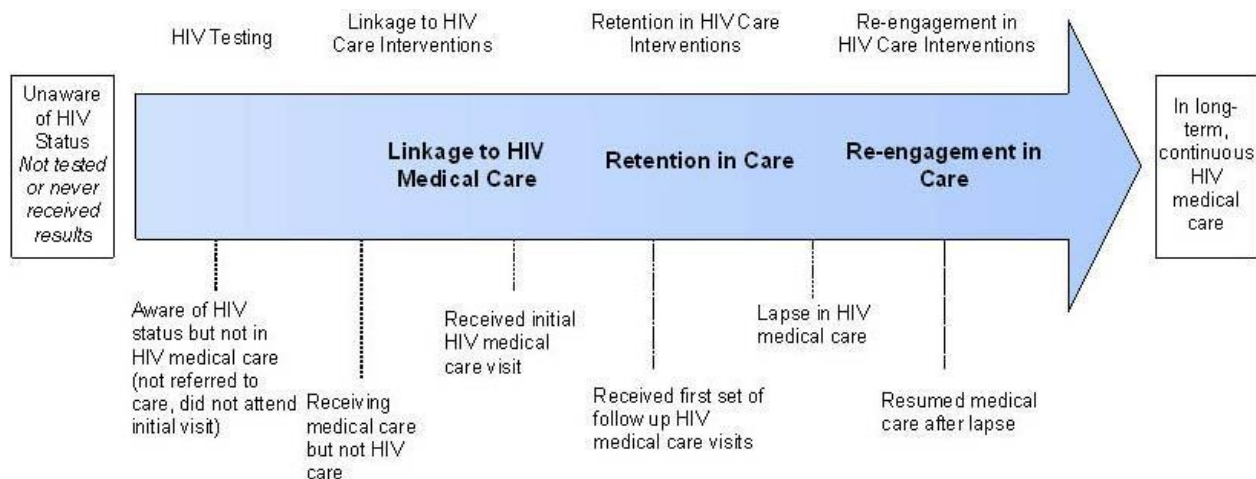


Figure 2.1: The continuum of engagement in HIV medical care (Cheever, 2007)

2.2.1 Initial Engagement in HIV Care

Effective linkage to care is of utmost importance as a person's first encounter with the healthcare system may have a profound impact on their decision and perceived ability to pursue consistent medical care. With scale up of ART programs, attention is going beyond expanding HIV adherence to antiretroviral medications to include engagement and retention in medical care (Thompson et al., 2012).

Engagement and retention in medical care after a diagnosis of HIV infection is essential to initiate lifesaving ART and facilitate the delivery of important prevention messages for reducing HIV transmission. Failure to engage and be retained in HIV care can be associated with negative outcomes for both the individual and the community. HIV treatment continuum or cascade is a dominant paradigm in engagement in care research (Gardner et al., 2011).

This continuum outlines key steps in the successful treatment of HIV-infected individuals, focusing specifically on diagnosis, linkage to care, retention in care, initiation of ART and achievement of an undetectable viral load. In recent years, there has been increased emphasis on the continuum given the potential for treatment as prevention, as clinical data demonstrate dramatically reduced risk of HIV transmission in the setting of virologic suppression (Cohen et al., 2011) and this can be achieved when a client is retained in care.

2.2.2 Retention of HIV infected persons in care

While ART programs in resource-limited settings have expanded treatment and reached millions of PLHIV, retaining patients in care is a critical challenge, with only 60% of patients retained in care after two years of ART. This undermines efforts to optimize patient and program outcomes (Rosen, Fox, & Gill, 2007). ART provision can be effective and successful only if patients are retained in care over time. Patients who are not retained in care are more likely to develop drug resistance, or risk of getting opportunistic infections as a result of treatment failure and necessitate hospital care and more expensive second-line treatment (Giordano et al., 2007).

Retention is also a critical issue for ART programs from a cost-effectiveness point of view. As programs are trying to maximize the impact of limited resources and increase value for money, a failure to ensure good retention in care is costly for both the program and the patient (WHO, 2011). As the scale up of ART programs continues, an understanding of factors influencing retention in care is essential to assist in implementing effective strategies. This study sought to understand these factors associated with retention in HIV care so as to mitigate them the barriers and enhance the facilitators.

2.2.3 The Challenge of Defining Retention in care

Definitions of retention in care vary greatly; some stakeholders refer to linkage to care to describe a concept that others capture within the definition of retention. There appeared to be differences within and between countries in these definitions (Fox & Rosen, 2010).

The Kenya HIV quality indicator framework defines retention as clients who attends at least two visits in the last six months (KHQIF, 2014).

Retention in HIV medical care can be measured and conceptualized in the following ways: Missed clinic visits, Clinic visit adherence and visit Care constancy. The selection of a retention measure may be based on a number of factors which may include the purpose for measuring retention in care, the type of clinic visit data that are available, clinic scheduling practices, and computational issues (Mugavero, Davila, Nevin, & Giordano, 2010). Commonly used retention measurement by clinical and public health researchers is missed clinic visits. Regardless of the number of scheduled visits, this measure captures the number of missed visits during a specified time period and they are typically defined as the number of clinic visits missed and do not include canceled or rescheduled visits in the retention measurement (Horstmann, Brown, Islam, Buck, & Agins, 2010). Clinic visit adherence is a retention measurement that is derived from missed clinic visits and it involves the use of visits scheduled as well as visits missed or attended. Visit adherence is a proportion that captures the number of completed visits in the numerator and the number of all scheduled visits in the denominator and is normally presented as percentage. Visit non-adherence is similar to visit adherence, but instead of the number of completed visits in the numerator, the number of missed visits is used (Mugavero et al., 2010).

The concept of retention in care is the sense of continuity and receipt of whatever care is appropriate at relevant points in time. It is often assumed that patients who are LTFU have stopped taking their treatment, whereas those who are retained in care are continuing to take their treatment as prescribed. Yet, LTFU and retention-in-care do not mean the same thing hence cannot be assumed to be the inverse of each other. As some could be lost to care but are on follow up at another site; silent transfers. A standard and consistent definition of retention and LTFU is needed to facilitate communication between programs, consistent data monitoring and evaluation nationally and globally. Definitions of LTFU are not standardized across studies with respect to time since last visit, and most studies do not account for such patients who interrupt, but then return to care (Chi et al., 2011).

2.2.4 Importance of retention in HIV care

Identifying PLHIV, supporting linkage to HIV prevention and care services, and early initiation of ART among those eligible, and lifelong care are key elements of the World Health Organization and United Nations Program on HIV/AIDS strategy towards achieving universal access to treatment for PLHIV (UNAIDS, 2014). For PLHIV to significantly benefit from HIV care and treatment they are needed to complete sequential steps from HIV testing and diagnosis, linkage and retention in care, initiation and adherence to ART (Fleishman et al., 2012).

Retention in care is critical to achieving these steps as it provides opportunity to monitor response to HIV therapy, offer and deliver prevention services and social support (Fleishman et al., 2012). Retention in care improves survival and reduces risk of HIV transmission but lost to care poses a challenge to this as it increases risk of morbidity and mortality (Cornell et al., 2014; Geng et al., 2010).

Despite the rapid scale up of HIV care and treatment programs, the challenges of attrition and retention into medical care has risen and it is facing the national programs (Cornell et al., 2014). A meta-analysis of 33 studies in SSA showed retention on ART at 3 years was 72% (Fox & Rosen, 2010), while in pre-ART care; 28 studies showed: HIV testing to receipt of CD4 count results and clinical staging 59% (35%-88%); Staging to ART eligibility 46% (31%-95%) and ART eligibility to ART initiation 68% (14%-84%) (Rosen & Fox, 2011). This shows that more clients are lost during the Pre ART period compared to the ART period but still during the ART period it is significant hence attention should be focused in both periods.

2.3 Proportion of retention in care among people living with HIV

2.3.1 Retention in care during Pre-antiretroviral therapy period

Clients who have not been initiated on ART (Termed as ART-naïve) have been found to be at higher risk of stopping and defaulting from care as compared to patients on ART

(Ahonkhai et al., 2012; Alamo et al., 2012). ART-naïve patients are likely to require less frequent follow-up visits and often feel well and are asymptomatic (Mulissa, Jerene, & Lindtjørn, 2010; Pati, Lahuerta, Elul, Okamura, Alvim, Schackman, Bang, Fernandes, Assan, Lima, et al., 2013). Demanding pre-ART requirements such as adherence counseling, HIV-status disclosure, and laboratory tests negatively influence retention rates (Alamo et al., 2012). Where resources are limited, greater emphasis is often given to following-up patients taking ARVs due to concerns about poor adherence and treatment failure, drug resistance, and death (Geng et al., 2010).

Studies conducted in SSA shows that linkage and retention to care is low. Timely entry into HIV care after an HIV diagnosis is made has been reported to be less than 50%; while retention to care and continuous engagement of patients in HIV care has been shown to decrease from 86% at 12 months to 72% at 60 months (Fox & Rosen, 2010). To adequately address these challenges of timely entry into HIV care and retention, there is a need to understand what factors are associated with retention into HIV medical care. Timely engaging of HIV infected patients into care after diagnosis has a great impact on efforts towards zero new infections.

In Kenya HIV-infected adults and adolescents who were aware of their HIV status, enrolment in HIV care was high (89.3%). Of those enrolled in HIV care, 79.4% enrolled within three months of HIV diagnosis. Overall, 60.5% of all HIV-infected adults and adolescents eligible for ART were taking ART (KAIS,2012). Around 40% of PLHIV who need ART are not on it and this is risky as they could be sources of new infections. Studies in the Pre ART period have demonstrated significant high levels of patient attrition. Strategies to address attrition have focused on the ART period. Retention to care during ART is well documented and most programs have clear mechanisms on how to follow up such patients. For instance a study conducted in Kenya found out that text messages sent to clients as reminders improves adherence to ART and also helps patient adhere to their appointments and subsequently being retained in care (Lester et al., 2010). However no similar study has been conducted to address Pre-ART needs. With loss of patients at every

stage of HIV continuum especially in the pre ART period is a major driver of poor Programme on retention to care (Fox & Rosen, 2010).

Evidence from a pre ART tracking study done in Uganda showed that of those LTFU during pre-ART, 31% were deceased. Of those alive and reached, 37% had disengaged from care with 63% accessing care elsewhere, which is silent transfers, hence are retained in care somewhere else. It also noted that attrition rates were significant after being assessed as ART eligible with approximately 21% LTFU at 12 months after becoming ART eligible by CD4 count (Geng et al., 2013).

Significant attrition levels could be because of lack of structure and services provided for PLHIV in this period, for instance among HIV-infected adults, and adolescents who were aware of their infection, 79.4% reported they had ever received a CD4 cell count test (NASCOP, 2011). Of concern is that these persons are not sick and have no symptoms which keeps them away from being engaged in care. HIV infected persons who are asymptomatic and absent from care or lost to care maybe at risk of transmitting HIV (Cohen et al., 2011). As by and large source of new HIV has been projected to come from asymptomatic PLHIV. Although there are well described support packages of care for HIV infected persons, there is little agreement and engagement on a set of strategies for pre ART services. In practice this translates to poor retention of clients (CDC Kenya, 2015).

2.3.2 Retention in care during antiretroviral therapy Period

Patient retention is critical in monitoring and evaluating ART performance. For a cohort of ART recipients, retention is understood as the proportion of patients known to be still receiving ART (the proportion who have not died nor been LTFU) at a given time after ART initiation (WHO, 2011). In 2008, the retention rates in SSA were 75% and 67% at 12 and 24 months, respectively (Tassie et al., 2010). Rate of retention for PLHIV started on ART has been found to reduce with time progression. At 12 months retention rate is higher (about 92%) and by month 60 it reduces to 70%. This requires measures that are

effective to tackle with loss to follow up and mortality amongst PLHIV on ART (NASCO, 2011).

A study conducted in Kenya and Malawi found out that overall Programme attrition was 43% for Malawi and 33% for Kenya. Restricting cohort evaluation to ART (as is usually done) underestimates overall Programme attrition by 38% in Malawi and 36% in Kenya. Considerable attrition occurs during the preparation phase of ART, and Programme evaluations confined to on-treatment analysis significantly underestimate attrition (Zachariah et al., 2011).

While chronic LTFU implications and interruption of ART has received significant attention and it includes increased risk of treatment failure and death, the consequences of brief interruptions in care, which may include any combination of non-compliance with clinical visits, laboratory assessments, or ART, are less certain and little is known (Kranzer & Ford, 2011). Two randomized trials done in resource-limited settings suggest that when compared to clinical monitoring alone routine laboratory monitoring plays an important role in the early recognition of treatment failure and prevention of progression to AIDS and death (Mermin et al., 2011; Walker et al., 2010). And this kind of monitoring can only be done while a patient is retained in care, thereby reducing risk for poor outcomes.

Barriers to ART adherence shed considerable light on the retention problem, as adherence means not only following dosing regimens but also being able to refill prescriptions. Since prescriptions are refilled as part of routine follow-up visits in Africa, barriers to adherence and retention overlap; scheduled appointments at HIV CCC in Kenya are planned to match with prescription refills (NASCO, 2011). Key adherence barriers identified through previous research that also bear upon retention include: Travel distance to clinic sites and associated costs, stigma and fear of disclosure, competing demands for scarce resources, religious and cultural beliefs, and unanticipated obligations and events such as attending a family funeral (Tuller et al., 2010).

2.4 Knowledge and perceptions regarding retention in HIV care

Knowledge of HIV care continuum has been identified to be key in achieving undetectable viral loads for patients infected with HIV. Information such as initial HIV diagnosis, linkage to care, retention in care, receipt of ART, and achievement of undetectable level viral load (Liau et al., 2013). Knowledge of where to access HIV testing is key in efforts to achieve zero new infections and zero AIDS-related deaths (UNAIDS, 2010). Assessing patients' perceptions of the quality of care not only provides information about the actual experiences but also reveals which quality aspects patients regard as most important (Zuidgeest, Strating, Luijkx, Westert, & Delnoij, 2012).

Patient satisfaction and knowledge of retention in HIV care are some of the vital components for the success of any healthcare program if they are to achieve desired clinical outcomes. A qualitative study conducted in South Africa on patient satisfaction with HIV treatment found out that overall patient satisfaction was high but patients expressed some dissatisfaction with certain dimensions of the quality of care, including inability to talk to health workers about their treatment and problems and time spent in queues waiting to be examined (Chimbindi, Bärnighausen, & Newell, 2009). The patients' perceptions of the quality of care and their satisfaction with this may affect health outcomes. This could lead to positive perceptions, compliance and adherence to ARV treatment (Ndou, Maputle, & Risenga, 2016).

2.5 Factors associated with retention in HIV care

2.5.1 Transportation and distance to clinic

It has been found that distance to the clinic and transport costs are major obstacles to retention in care in a wide variety of settings in Africa. A study conducted in Uganda, among 111 patients LTFU, the most common reasons for absence were lack of transportation in 50% and excessive distance in 42% (Geng et al., 2010). A multisite analysis conducted by International Center for AIDS Care and Treatment (ICAP) in

Western, Eastern and Southern Africa using a 6 month absence as the outcome, found that if travel time to clinic exceeded 2 hours, the risk of non-retention was doubled (Rabkin, Austin, & Nash, 2010). In Western Kenya, one study found that, travel time among pre-ART patients was significantly associated with failure of retention among women (Ochieng-Ooko et al., 2010). The consistent relationship between transportation and distance on retention prompted a randomized trial to be conducted on retention in care. This trial, conducted in Uganda, individuals were randomized to receive a cash transfer of 10,000 to 15,000 Uganda Shilling (\$5-\$8) to be used for transportation and others did not receive. It found out only 18% patients were LTFU from the intervention group compared to 34% lost from the control group (Emenyonu et al., 2010). This shows that transportation to the clinic and distance affects retention in care.

2.5.2 Competing life activities/priorities

Clinic attendance is one of the measures of retention in care. A study conducted on barriers and facilitators of retention in care found out that other life activities which are a priority takes up their time thereby hindering adherence to scheduled clinic appointments in both those individuals retained and not retained in care. Obstacles commonly mentioned included: Caring for children or elderly family members, work, and school. Getting time off for appointments from work was a challenge and some participants mentioned struggling to find one that was flexible enough to allow them to successfully manage their HIV infection (Yehia, Stewart, et al., 2015). Among poor families, work and childcare responsibilities competed with retention in care. In over 50,000 patients in the Academic Model Providing Access to Health Care (AMPATH) programs in Kenya, 21% of women cited family commitments for missing a clinic appointment and 24% of men cited work commitment (Ochieng-Ooko et al., 2010).

2.5.3 Social support, Stigma and Disclosure

Social support from family members and friends has been identified to meaningfully facilitate retention in care (Tiruneh, Galárraga, Genberg, & Wilson, 2016). It also assists in medication adherence and helpful in fighting stigma, reducing the work involved preventing unintended disclosures, establishing a community in which to share ideas, and obtaining resources (WHO, 2011)

Pervasive stigma and discrimination from family members, friends and community have been identified to contribute to LTFU of PLHIV on treatment. To ensure maximum retention in the HIV/AIDS care continuum, there is the need for stigma reduction policies to accompany HIV prevention and treatment efforts (Layer et al., 2014). An e- survey conducted by WHO in 22 countries in Africa, Asia, Latin America and Europe established the importance of increasing retention through better follow-up mechanisms, counselling, clinic based support services including ART adherence support and psychosocial support(WHO, 2011).

Social support interventions for vulnerable groups appear to be promising interventions to improve the retentions. In a study from Kenya, targeted program providing social support for youths found retention was better at the intervention clinic with 70% remaining in active care versus 55% at the general site for same age group who had no support (Monahan et al., 2009). Disclosure which has been hypothesized to be a marker of social support was found to be associated with a 70% rise in the odds of retention in 3362 patients in the Prevention of mother to child transmission plus network supported by ICAP (Rabkin et al., 2010).

2.5.4 Lost to follow-up among people living with HIV

The easiest definition of LTFU are patients lost to care with unknown outcomes and their status is not known if they are dead or alive. There are many causes of LTFU along the continuum, including stigma in the community and from healthcare staff, patient costs

(transportation, loss of income), service delivery factors (prolonged waiting times, high frequency of clinic visits, poor linkage between services, lack of or poor patient monitoring systems, poor integration, stock-outs) patient factors and beliefs (limited perception of treatment issues, denial, alternative health beliefs, lack of disclosure to partner/family), and most importantly, overburdened, under-staffed healthcare systems (Fox & Rosen, 2010).

Significant characteristics associated with lost to follow-up is: younger age, male sex, loss after one visit, unknown partner HIV status, lack of disclosure and advanced HIV disease (Alamo et al., 2012; Stolka et al., 2016). Patients who transfer out of a facility often involves treatment and care interruptions which may lead to advanced worsened disease outcomes upon return to care at a later date (Ahonkhai et al., 2012). A tracking system with improvements to national health information systems is important in ensuring PLHIV who transfer or lost to care are monitored and followed up. Patient tracking as a means of establishing causes of LTFU is important at a local level in order to improve service provision (Geng et al., 2010). The challenge is that, such services are not easily available in resource limited settings where it's needed the most (Rosen & Fox, 2011).

The test and treat strategy implementation for all PLHIV as per UNAIDS (2014) guidelines, for improved long term health outcomes and prevent HIV transmission calls for the need to prioritize retention in care as an essential component for HIV providers and all stakeholders.

CHAPTER THREE

MATERIALS AND METHODS

3.1 Study site

The study was conducted at Pumwani comprehensive care Centre. The Centre is located in Eastland's area of Nairobi in Kamukunji Sub County and mostly serves the resource constrained populations in its vicinity. The catchment of the clinic however, is not confined to the vicinity but extends to the other sub counties in Nairobi and outside.

Among the services offered in the clinic include HIV testing and counseling, adherence counseling and assessment of ART eligibility, provision of ARVs, treatment of opportunistic infections, psychosocial support groups and follow ups for clients, defaulter tracing through phone tracing, physical tracing and home visits. In November 16 -March 2017 when the study was undertaken, Pumwani comprehensive care Centre had 2704 clients who were active in care.



Figure 3.1: Map of Kenya (Source; Google, 2018)

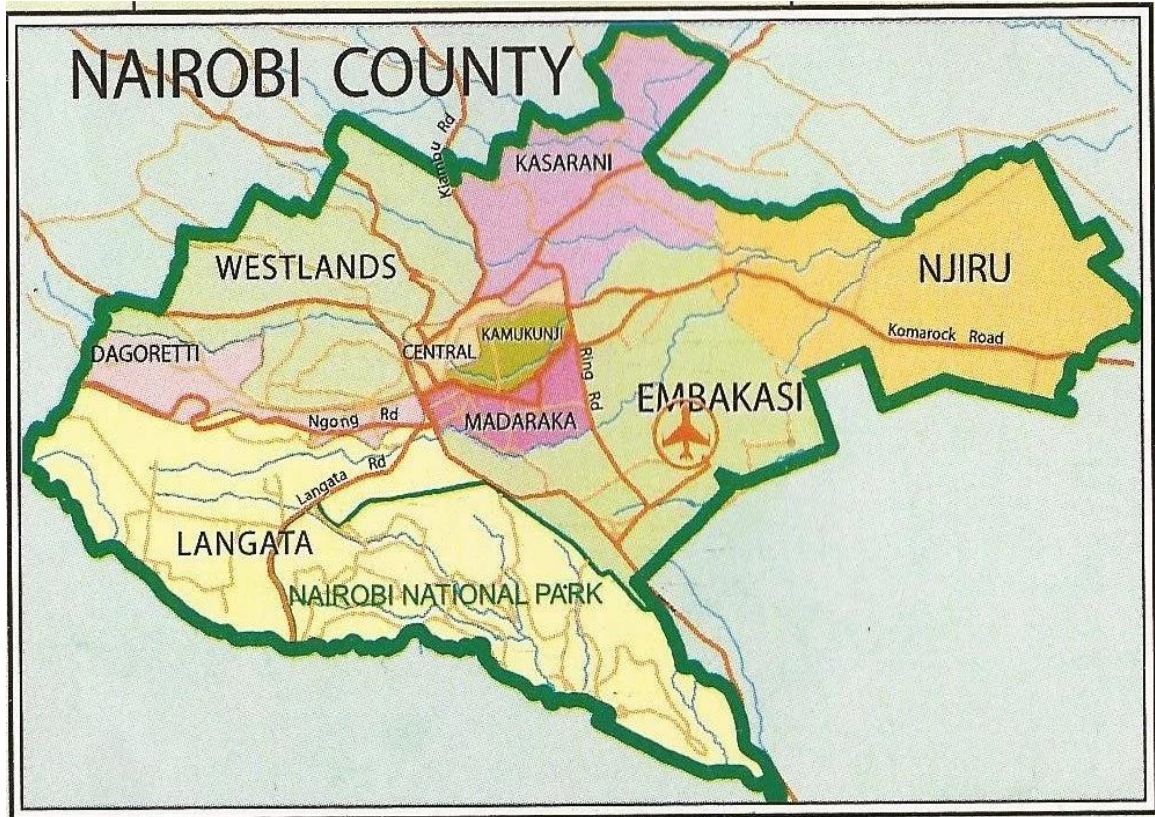


Figure 3.2: Map of Nairobi County; (Source; Google, 2018)

3.2 Study design

A cross sectional study design was adopted and utilized both quantitative and qualitative techniques.

3.3 Variables

3.3.1 Independent variables

The independent variables were knowledge, perceptions, factors and socio-demographic characteristics

3.3.2 Dependent variable

Dependent variable was retention in care

3.4 Study population

HIV positive individuals over 18 years receiving care at Pumwani comprehensive care Centre for more than six months since enrollment in care.

3.5 Enrollment Criteria

3.5.1 Inclusion Criteria

Adult HIV positive patients (≥ 18 years of age) who have been accessing care and treatment in Pumwani comprehensive care Centre for six months and above, and gave their consent to participate in the study.

3.5.2 Exclusion Criteria

- i. Newly enrolled clients (less than six months)
- ii. Transfer in clients

3.6 Sample size determination

The clinic had 2704 active clients enrolled into the HIV care as of September 2016. From this population the sample was drawn. The sample size was determined using Fisher's formula (1998) which is the recommended formula for cross-sectional studies. The assumption was that the sample was representative, the sampling error was small and that the results are generalizable.

For populations that are large (that is 10,000 and above), sample size for prevalence is estimated as:

$$n = \frac{Z^2 * p(1 - p)}{e^2}$$

Where

n is the sample size for target population >10,000,

Z² is the abscissa of the normal curve that cuts off an area α at the tails (1 - α equals the desired confidence level, e.g., 95%),

e is the desired level of precision,

p is the estimated proportion of subjects adhering to clinic appointments in the target population,

The study desired a 95% confidence level and $\pm 5\%$ precision. The study assumed $p=0.5$ since there was no similar study in the target group and study area, substituting the above parameters, the sample size became:

$$n = \frac{1.96^2 * 0.5(1 - 0.5)}{0.05^2} = 384$$

The accessible population was 2704 persons in this study. According to fisher's formula a study population of less than 10,000; adjustment formula is used.

Where **n** is the sample size and **N** is the population size.

$$n = \frac{n_0}{1 + \frac{(n_0 - 1)}{N}}$$
$$= \frac{384}{1 + \frac{(384-1)}{2704}} = 336.36 = 337 \text{ participants}$$

n= 350 participants (350 participants were recruited to cater for the non-responses)

3.7 Sampling procedure

Study participants were HIV positive patients receiving services at Pumwani Comprehensive care Centre. From the facility health records a total of 2704 clients were active on care as of September 2016, hence this was used to form the sampling frame. Systematic random sampling method was used to select every 8th patient who met the inclusion criteria. The interval was calculated by taking the number of adult patients enrolled by end of May 2016 which was six months prior to this study and was 2654. This was then divided by the sample size to get 8 ($2654/337= 8$). This process continued on every clinic day until the sample size of 350 was reached. The participant was taken through the study protocol and informed that participation in the study was voluntary and are free to withdraw from the study at any point.

Purposive sampling was used to select focus group discussions participants where each group comprised 9 participants.

3.8 Data collection tools

Questionnaire and focus group discussion guide were used

3.8.1 Questionnaire

Structured questionnaire was administered by trained research assistants. They were used to capture the socio-demographic information and data on clients' level of knowledge, perceptions and factors associated with retention in care. Those who participated in the questionnaire were not invited to participate in the focus group discussions.

3.8.2 Focused group discussion

A focus group was conducted where the two moderators worked together. One moderator asked the questions and led the session, while the other moderator ensured that all questions were asked and any new evolutions were discussed further. A guide was used to gather qualitative data on knowledge and perceptions regarding retention in care from the participants such as patients' experiences with ART care and treatment, barriers to retention in HIV care and reasons for discontinuation in HIV care leading to poor retention. Each focus group discussion (FGD) was audio-recorded and fully transcribed. Two FGD with 9 participants in each group were conducted comprising clients with history of missed appointments and those without. The proceedings were conducted by the researcher while an assistant was taking notes and tape recording.

3.9 Pre-Testing of study tools

The questionnaire was pretested among 10 HIV positive clients who were not involved in the study in Pumwani comprehensive care Centre. Appropriate corrections was then made on the questionnaire.

3.9.1 Validity

The validity was ensured by correct large sample size selection through systematic sampling. Careful planning and the study design also enhanced the validity of the study. In addition, the University supervisors further reviewed the questionnaire to ensure content validity- accuracy, relevance and language appropriateness before pretest.

3.9.2 Reliability

Reliability of the study tool was ensured through use of a well-designed questionnaire including daily checking and correction of completed questionnaires. In addition, research assistants were trained and supervised during data collection.

3.10 Data Management and analysis

3.10.1 Quantitative data

All questionnaires were reviewed on daily basis to ensure they are completed appropriately. Data collected was entered into an Excel spreadsheet in a password protected computer. Back-up copies were stored in an external hard drive and compact disc which was in sole custody of principal investigator. The filled questionnaires were filed and stored in a locked cabinet for verification during analysis.

Further cleaning was carried out after entry using frequency distributions and cross-tabulations until no more errors were detected. In order to achieve the objectives of the study, data analysis was carried out in three steps; Univariate analysis, bivariate analysis and multivariate analysis: Univariate analysis involved frequency distributions for categorical variables and descriptive statistics (means, medians) for continuous variables stratified by retention to primary HIV care. Categorical variables (such as sex, education level) were presented using bar charts and frequency distribution tables. Histogram was used to present continuous variables such as age and time to enrollment. Univariate analysis was used on the characteristics of the study participants.

Bivariate analysis involved testing the association between the hypothesized predictor variables (such as age, education level, sex) and the dependent variable (that is retention to primary HIV care). Parametric tests were used as the primary analysis. This included a 2-tailed Student's t-test for independent samples which was used for all comparisons of the mean of continuous variables between the two groups. A chi-square test was used for all comparisons of categorical variables between the groups, except when the expected values in the 2x2 table will be below 5. Fisher's exact test was used in this scenario.

In multivariate analysis all variables found to have a significant relationship with retention to primary HIV care appointments at bivariate analysis were used in performing logistic regression model. Logistic regression model established factors associated with retention to primary HIV care for PLHIV at Pumwani CCC.

Tests with p-value < 0.05 alpha level of significance was considered to show statistical significance. All p-values, odds ratio and confidence intervals were reported to three decimal places with p-value less than 0.001 reported as $p < 0.001$. Statistical Package for Social Sciences Programme (SPSS) version 20.0 was used for data analysis.

3.10.2 Qualitative data

All interviews were audio recorded, transcribed, and analyzed for themes and patterns. Descriptive analysis of the sample was conducted. The process developed themes and sub-themes that emerged from the ground based on responses to the questions. First, an initial set of transcripts were reviewed line-by-line to generate a working coding scheme. Then, using this scheme, it was independently coded. It was double-coded to check for inter-rater reliability. Charting and mapping of the data was used to illustrate the views and experiences of the respondents and for interpretation of the data. Data presentation was through verbatim.

3.11 Ethical Considerations

The study received approval from Kenyatta National Hospital /University of Nairobi Ethics Review Committee. Permission to access Pumwani CCC and patients was sought from Medical superintendent and the management of Pumwani clinic. An informed consent was obtained from eligible study participant.

The questionnaires were serialized and the respondents were not required to write their names or any other identification numbers. Information provided was treated with utmost confidentiality and this was communicated to the respondents.

Assurance was given to the respondents concerning the information collected that; it will be used only for the intended purpose of determining factors associated with retention in care amongst PLHIV in Kenya and no plans whatsoever is intended to victimize anybody.

The participants were informed about the purpose of the study and how it would be carried out. Participation was voluntary and participants were informed that they could leave the interviews at any time. Confidentiality, anonymity and privacy was fully guaranteed by a unique number and no names were used. All data obtained from the participants was kept under lock and key.

CHAPTER FOUR

RESULTS

4.1 Socio demographic characteristics of participants

A total of 350 HIV positive clients participated in the study. Demographic data shows 71.4% of the study participants were female while 28.6% were male, with a mean age of 40 years. About 63% were married, 43.8% had attained primary and lower level of education with 51.1% being self-employed as shown in table 4.1.

Table 4.1: Socio demographic characteristics of participants

Characteristics	Total	Retained		P-Value
		No (116(33.2%))	Yes (234(66.8%))	
Gender(n=350)				
Male	100(28.6%)	38(32.8%)	62(26.5%)	0.222
Female	250(71.4%)	78(67.2%)	172(73.5%)	
Age in years (Mean(SD))	40(9.2)	39.4(8.4)	40.3(9.5)	0.38
Marital Status(n=350)				
Single	49(14.0%)	14(12.1%)	35(15.0%)	0.556
Married	219(62.6%)	74(63.8%)	145(62.0%)	
Widowed	29(8.3%)	9(7.8%)	20(8.5%)	
Divorced	21(6.0%)	5(4.3%)	16(6.8%)	
Separated	32(9.1%)	14(12.1%)	18(7.7%)	
Level of Education(n=347)	(n=13 missing due to non-response)			
Primary or less/none	152(43.8%)	46(40.0%)	106(45.7%)	0.603
Secondary	144(41.5%)	51(44.3%)	93(40.1%)	
College	51(14.7%)	18(15.6%)	33(14.3%)	
Occupation(n=348)	(n=12 missing due to non-response)			
Employed(Formal)	123(35.3%)	48(41.4%)	75(32.3%)	0.17
Self employed	178(51.1%)	57(49.1%)	121(52.2%)	
Casual worker	15(4.3%)	2(1.7%)	13(5.6%)	
Unemployed	32(9.2%)	9(7.8%)	23(9.9%)	
Monthly income(n=326)	(n=24 missing due to non-response)			
0-5000	101(31.0%)	29(26.6%)	72(33.3%)	0.4803
5001-10000	93(28.5%)	33(30.3%)	60(27.8%)	
10001 and above	132(40.5%)	48(43.6%)	84(38.9%)	

SD: standard deviation, n: sample size

4.2 Proportion of retention

Overall the proportion of retention in care for this study was 66.8% (figure 4.1). Of those retained 73.5% were females, 62.6% of participants were married and 45.7% had attained primary education, while 52.2% retained were in self-employment and 39.2% earning at least ten thousand shillings per month. There was no significant association in the proportion of retention among socio demographic factors (P value of >0.05).

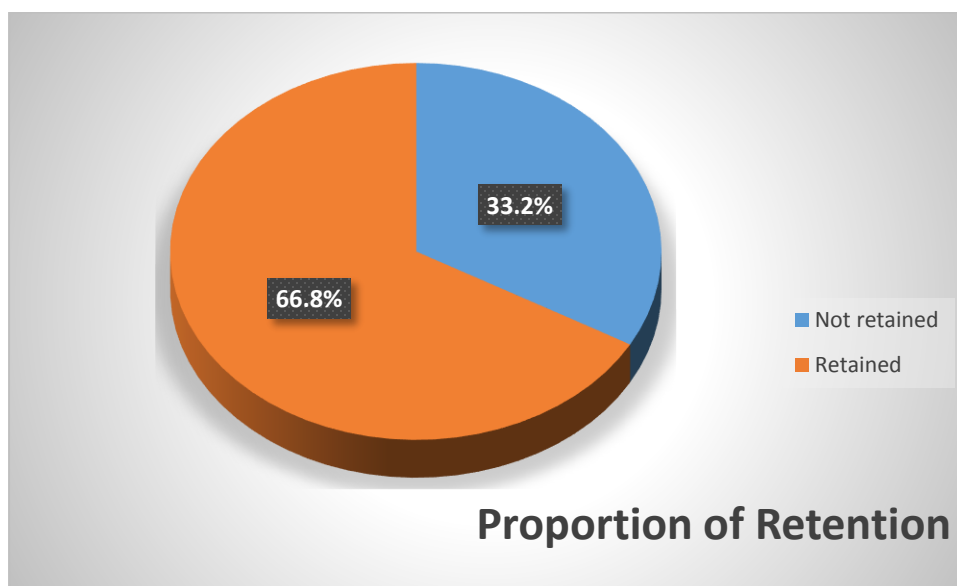


Figure 4.1: Proportion of retention in care among HIV positive adults

4.3 Knowledge of retention in HIV care

Retention in HIV care begins from when a person with HIV is linked successfully to services, continuous engagement in care to retention in lifelong ART care. Findings showed that 70.3% of participants retained in care knew they could be tested by a health care worker through provider initiated testing and counselling (PITC) compared to those who said they knew they could know their status voluntarily and this was statistically significant (P-value 0.028). Three quarter of the participants (75%) were aware that they needed to be enrolled in care within three months after diagnosis of HIV. Similarly, 70.7% of clients retained were knowledgeable on the frequency of seeing a health care worker at

least four times a year. Majority, (93.7%) reported to be aware of dangers of missing appointments and counselled on it, yet 66.8% were retained in care (Table 4.2).

Table 4.2: Knowledge regarding retention in HIV care

Retained				
Factors	Total	No	Yes	P-Value
Knowledge of where to test for HIV (349)				
VCT	100(28.7%)	42(42%)	58(58%)	0.028
PITC	249(71.3%)	74(29.7%)	175(70.3%)	
Duration of enrollment in care after HIV diagnosis (n=350)				
Immediately	129(37.0%)	41(31.8%)	88(68.2%)	0.36
Less than a week	80(22.9%)	26(32.5%)	54(67.5%)	
1-4 weeks	49(14.0%)	13(26.5%)	36(73.5%)	
1-3 months	20(5.7%)	5(25.0%)	15(75.0%)	
> 3 months	71(20.3%)	30(42.3%)	41(57.7%)	
Knowledge of frequency of visiting a HCW in a year (n=350)				
less than twice	16(5.2%)	6(37.5%)	10(62.5%)	0.666
Thrice	50(16.2%)	17(34%)	33(66%)	
more than 4 times	242(78.6%)	71(29.3%)	171(70.7%)	
Aware of dangers of missing appointment and counselled on it (n=350)				
No	22(6.3%)	7(31.8%)	15(68.2%)	0.892
Yes	328(93.7%)	109(33.2%)	219(66.8%)	

4.3.1 Knowledge of HIV disclosure and support received

About ninety percent (89.7%) confirmed to have disclosed their HIV status to someone while (10.3%) had not disclosed their status to anyone. Amongst those who had disclosed their status, (66.6%) of clients were retained in care and they received support. There was statistical significance for clients who receive social support (P value 0.008) (Table 4.3).

Table 4.3: Disclosure of HIV status and support received among the respondents

Retained				
Factors	Total	No	Yes	P-Value
Disclosed HIV status (n=350)				
Yes	314(89.7%)	105(33.4%)	209(66.6%)	0.728
No	36(10.3%)	11(30.6%)	25(69.4%)	
Support received (n=314)				
Reminded to take drugs				
No	157(50%)	53(33.8%)	104(66.2%)	0.905
Yes	157(50%)	52(33.1%)	105(66.9%)	
Accompany Hospital				
No	295(93.9%)	98(33.2%)	197(66.8%)	0.746
Yes	19(6.1%)	7(36.8%)	12(63.2%)	
Financial support				
No	208(66.2%)	76(36.5%)	132(63.5%)	0.103
Yes	106(33.8%)	29(27.4%)	77(72.6%)	
Reminded appointment date				
No	271(86.3%)	91(33.6%)	180(66.4%)	0.895
Yes	43(13.7%)	14(32.6%)	29(67.4%)	
Social support				
No	235(74.8%)	69(29.4%)	166(70.6%)	0.008
Yes	79(25.2%)	36(45.6%)	43(54.4%)	

4.3.2 Knowledge of any other place you can get ART services

Study findings revealed that clients were keen on continuity of care whereby 58% of clients retained have ever sought care in other facilities. About 85% knew of where to access ART services in case they could not reach the clinic on their appointment day in order to continuously engage in care. Of those retained, 55.4% sought refill of ARVs, while 47.2% sought treatment of infections and 33.3% laboratory services. There is no statistical association between clients who have ever sought care elsewhere, type of services sought and retention in care (P value >0.05) (Table 4.4).

Table 4.4: Knowledge of other places you can get ART services

		Retained		
Factors	Total	No	Yes	P-value
Knowledge of any other place you can get treatment and refill of ARVs (n=350)				
No	61(17.4%)	25(21.6%)	36(15.4%)	0.152
Yes	289(82.6%)	91(78.4%)	198(84.6%)	
Have you ever sought care elsewhere since enrolled (n=350)				
No	269(76.9%)	82(30.5%)	187(69.5%)	0.054
Yes	81(23.1%)	34(42.0%)	47(58.0%)	
What services have you ever sought in other facilities(n=81)				
Treatment (n=81)				
No	45(55.6%)	15(33.3%)	30(66.7%)	0.078
Yes	36(44.4%)	19(52.8%)	17(47.2%)	
Refill (n=81)				
No	25(30.9%)	9(36.0%)	16(64 %)	0.467
Yes	56(69.1%)	25(44.6%)	31(55.4%)	
Lab Test (n=81)				
No	75(98.3%)	30(40%)	45(60%)	0.232
Yes	6(1.7%)	4(66.7%)	2(33.3%)	

4.4 Perceptions regarding retention in HIV care

About 92% of the participants thought missing clinic appointments was a risk factor however, 68.2% were retained in care. Similarly, 69.5% of clients retained perceived health care worker (HCW) as being good while 61.7% viewed HCW as average and only 2.2% said they stigmatize clients. A high proportion (94%) of participants retained perceived that the time spent for clinic services is enough (Table 4.5).

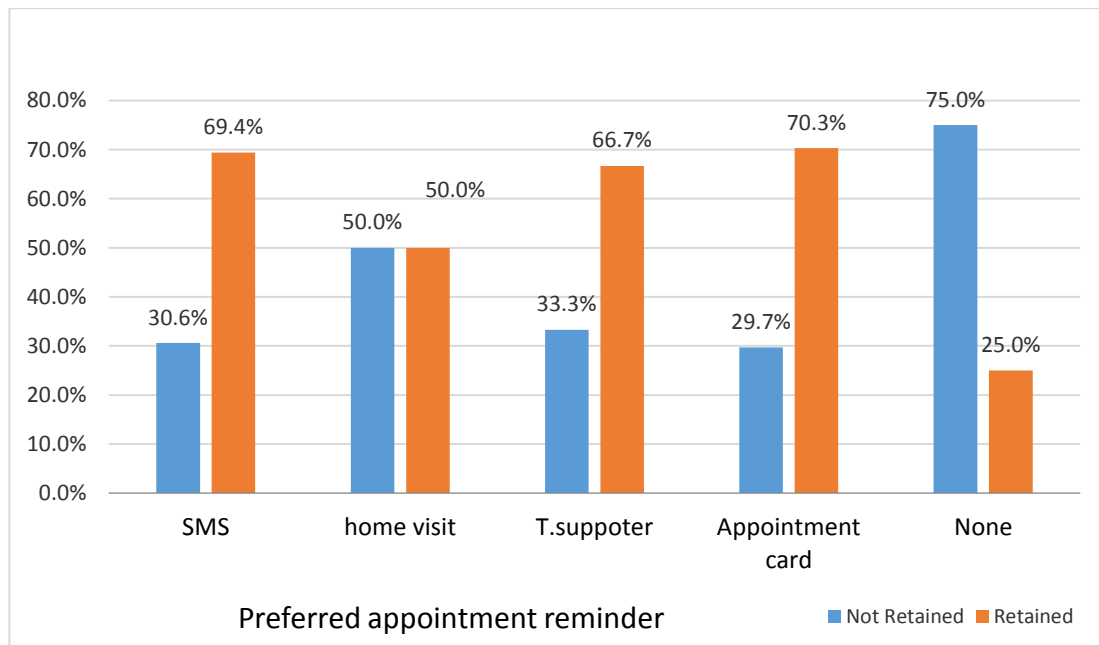
Table 4.5: Perceptions regarding retention in HIV care

		Retained		
Factors	Total	No	Yes	P-Value
Whether Missing appointment puts one's health at risk (n=350)				
No	29(8.3%)	14(48.3%)	15(51.7%)	0.071
Yes	321(91.7%)	102(31.8%)	219(68.2%)	
View towards HCW in Pumwani clinic (n=340)				
Good	226(66.5%)	69(61.6%)	157(68.9%)	0.358
Average	107(31.5%)	41(36.6%)	66(28.9%)	
They stigmatize patients	7(2.1%)	2(1.8%)	5(2.2%)	
Whether Time for clinic services is enough (n=350)				
No	19(5.4%)	5(4.3%)	14(6%)	0.516
Yes	331(94.6%)	111(95.7%)	220(94%)	

4.5 Factors Associated With Retention in HIV Care among HIV positive adults

4.5.1 Clinic Appointment reminder among HIV positive adults

Clinic attendance is key in the HIV treatment cascade and it is used to measure retention. Regarding appointment reminder, the participants preferred more than one method to be reminded to attend to their appointments. Of those retained, 70.3% chose an appointment card as a preferred mode, 69.4% text message service, 66.7% treatment supporter, 50% home visit and 25% didn't want to be reminded, these were almost three times of clients wishing to be reminded (figure 4.2).



T.

T-supporter-treatment supporter

Figure 4.2: Preferred appointment reminder for HIV positive adults

4.5.2 Travel distance and transportation costs to the clinic

Excessive distance to clinic leading to long travel time costs plays a role in retention. Results showed 44.4% of clients retained spent one hour to reach the clinic, 22.2% used two hours and 7.7% spent more than three hours. Fare spent to clinic was found not affecting retention significantly as participants spending more for bus fare were retained compared to those who spent less, where 73.3% spent more than 500 shillings and 67.3% spent less than 100 Kenya shillings (Table 4.6).

Table 4.6: Travel distance and transportation costs to the clinic

Factors (n=350)	Total	Retained		P-Value
		No	Yes	
Travel time to the clinic				
< 30 mins	95(27.1%)	35(30.2%)	60(25.6%)	0.411
1 hr	160(45.7%)	56(48.3%)	104(44.4%)	
2 hrs	70(20.0%)	18(15.5%)	52(22.2%)	
3 hrs	25(7.1%)	7(6.0%)	18(7.7%)	
Fare to clinic				
<100	205(58.6%)	67(32.6%)	138(67.3%)	0.746
100-500	115(32.9%)	41(35.7%)	74(64.3%)	
>500	30(8.6%)	8(26.7%)	22(73.3%)	

4.5.3 Appointment day at the clinic for HIV positive adults

Majority, (72.1%) retained reported to have used one to two hours on average to receive all the required services at the clinic and 83.8% said that the waiting time was average. However, there was no statistical significant association between appointment day at the clinic and retention in care (Table 4.7).

Table 4.7: Appointment day at the clinic for HIV positive adults attending Pumwani clinic

Factors (n=350)	Total	Retained		P-Value
		No	Yes	
Time spent to receive services at the clinic (n=350)				
< 30 mins	23(6.6%)	6(5.2%)	17(7.3%)	0.841
1-2 hrs	253(72.5%)	85(73.3%)	168(72.1%)	
2-3 hrs	66(18.9%)	22(19.0%)	44(18.9%)	
> 3hrs	7(2.0%)	3(2.6%)	4(1.7%)	
Comment on time used to receive services (n=350)				
Short	6(1.7%)	3(2.6%)	3(1.3%)	0.689
Average	283(82.3%)	92(79.3%)	191(83.8%)	
Long	43(12.5%)	16(13.8%)	27(11.8%)	
Too long	12(3.5%)	5(4.3%)	7(3.1%)	

4.5.4 Lost to follow up among HIV positive adults

Almost half, (47.4%) participants reported to have ever missed a scheduled clinic appointment, where 88% of the 47.4% reported to have missed appointments once or twice and 12% more than twice. About 30% percent missed for less than three months while 34.3% were lost to follow up for a period between three to twelve months and 36.2% for more than twelve months. During the period they were away from follow up, 65.2% said they were well, while 17.1% did not encounter any problem initially but later got sick and 17.7% were always sickly. Reasons for resuming clinic was: 42.5% were followed up, 26.5% accepted their status, 13.8% were sick and 17.1% returned back to town (Table 4.8).

Table 4.8: Lost to Follow-up characteristics among HIV positive adults

Follow up	Frequency (f)	Percentage (%)
Ever missed appointment(n=350)		
No	184	52.6
Yes	166	47.4
Number of times missed appointment (n=166)		
Less than twice	146	88
More than twice	20	12
Stop follow up(n=166)		
< 3 months	49	29.5
3-12 months	57	34.3
> 12 months	60	36.2
Health during lost to follow up(n=164)		
Well/Not sick	107	65.2
Always sickly	28	17.1
Initially well but later got sick	29	17.7
Reasons for resuming clinic (n=181)		
Followed Up	77	42.5
Accepted My Status	48	26.5
Was Sick	25	13.8
Came Back To Nairobi	31	17.1

4.5.5 Reasons for missing scheduled clinic appointments

About 54% of the participants with history of missing appointments reported that competing life activities hindered them from adhering to scheduled appointments at the clinic. Obligations such as getting time off work, travel up country for a burial or attend to the farm and nursing a sick relative were among the obstacles mentioned. While 13.3% reported that they were afraid of stigma and discrimination hence defaulted care. Eleven point five percent said they were tired of taking medications and the routine follow up hence missed appointments (Figure 4.3).

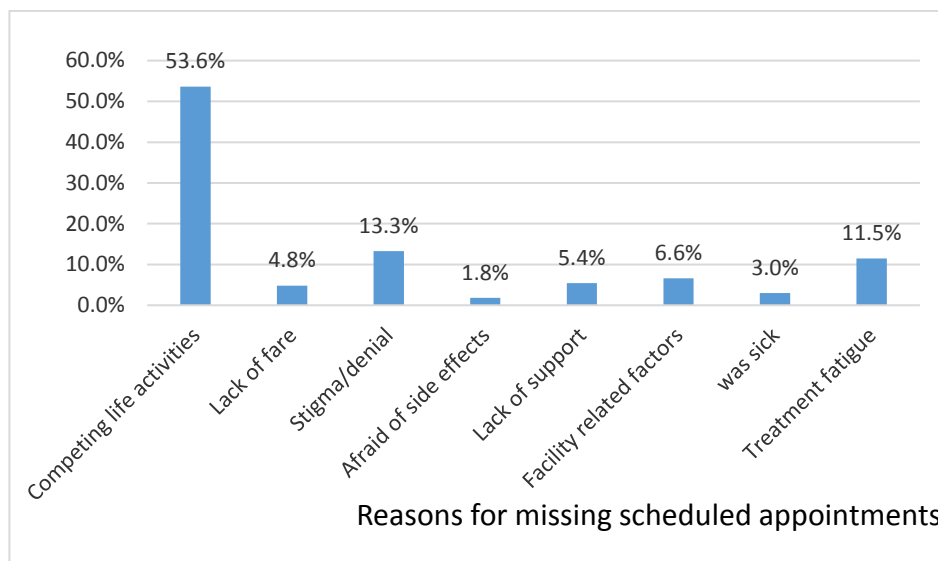


Figure 4.3: Reasons for missing HIV positive adults scheduled appointment among

4.5.6 Access to Care while lost to follow up

Participants on ARVs are more likely to be retained in care compared to those not on ARVs. Study findings showed, 42.3% of clients on ARVs who have ever missed a scheduled appointments were retained compared to 13% not on ARVs. This was of statistical significance (P-value of <0.001), while clients who missed appointments and

on ARVs, 71.6% missed taking them, 24.2% picked in another facility and 4.2% borrowed from a friend/family friend. Amongst those retained and continued to take their drugs despite missing their appointments; 75% borrowed and 43.5% picked in another facility (Table 4.9).

Table 4.9: Access to care while lost to follow-up among the participants

		Retained		
Factors	Total	No	Yes	P-Value
On ARVs when missed Appointments (n=166)				
No	69(41.6%)	60(87%)	9(13%)	<0.001
Yes	97(58.4%)	56(57.7%)	41(42.3 %)	
Access to ARVs when missed follow up(n=95)				
Missed taking drugs	68(71.6%)	42(61.8%)	26(38.2%)	0.336
Picked another facility	23(24.2%)	13(56.5%)	10(43.5%)	
Borrowed	4(4.2%)	1(25.0%)	3(75.0%)	

4.5.7 Univariate and multivariate analysis of factors associated with retention in care

The results showed that adjusting for potential confounders, variables like entry into HIV care, participants receiving social support and on ARVs when missed appointment were significantly associated with retention in care among participants. Patients initially engaged into care through PITC were significantly two times likely to be retained in care compared to those who are engaged through VCT (OR: 2.057; 95%CI [0.853-4.961]; p-value 0.028). Patients who were socially supported had a significant 10.3% chance of being retained in care compared to those who didn't have social support (OR: 0.103; 95%CI [0.023-0.4370]; p-value 0.008). Clients on ARVs were four times likely to be retained in care compared to not being on ARVs (OR: 3.965; 95%CI [1.632-9.733]; p-value <0.001) (Table 4.10)

Table 4.10: Univariate and multivariate analysis of factors associated with retention in care

Factors	Univariate Analysis			Multivariate Analysis	
	p-value	UnAOR	95% CI for UnAOR	AOR	95% CI for AOR
Entry point for HIV Testing					
VCT	0.028	1		1	
PITC		1.712	(1.058, 2.771)	2.057	(0.853, 4.961)
Supported Socially					
No	0.008	1		1	
Yes		0.496	(0.294, 0.839)	0.103	(0.023, 0.470)
On ARV when missed Appointment					
	<0.001				
No	1	1		1	
Yes		4.881	(2.175, 10.952)	3.994	(1.632, 9.733)

Note: OR = Odds ratio; 95% CI = 95% confidence interval, UnAOR and AOR = crude and adjusted Odds ratios respectively.

4.6 Qualitative analysis

4.6.1 Background information

Two FGDs were conducted with eighteen participants. Regarding sex, 66.7% participants were females and the mean age was 39 years. About 45% had attained primary education and 44.4% were self-employed. Nine participants had history of missing appointments. Selection was done through hospital social worker (Table 4.11).

Table 4.11: Background information of focus group participants

Characteristic	Number (n=18)
Gender	
Male	6
Female	12
Age (Mean, range)	39(22-56)
Education	
No formal education	5
Primary	8
Secondary	3
Tertiary	2
Occupation	
Unemployed	7
self employed	8
Employed	2
Student	1

4.6.2 Focus group discussions findings

Two focus group discussions were held with the participants and data was thematically analyzed. Some participants said to have never missed their appointments from the start, however, all reported encountering struggles in keeping up with routine follow up schedules at the clinic due to competing life activities. It was noted that clients not on ARVs missed appointments as there is no clear plan laid out for them and most of them are asymptomatic. All participants agreed that adherence counselling helps one to stay in care and should be given at all times.

The findings are presented under three thematic areas. The first objective was to describe knowledge and experience of HIV positive people in follow up and retention in care. The second objective was to describe perceptions and reasons for discontinuing care and the third objective was to describe what socio economic factors they perceive that affect retention in care (Table 4.12).

In addition, exploratory questions were used to ascertain what had been useful and challenging in retention in care, roles played by other people in the continuous engagement in care and eventually retention in care. Findings are presented as summary points and in some cases quotations are cited verbatim as stated by the respondents.

Table 4.12: Summary of qualitative findings among HIV positive adults

Theme	Sub themes
Knowledge ,experience in HIV care, follow-up and retention in care	Learning about the diagnosis and where to access services Disclosure of HIV status and adherence counselling
Perceptions and reasons for discontinuation of care	Perceptions for discontinuing Care Reasons for defaulting care Relationship with the health care worker
Socio economic factors perceived to affect retention in care	Travel time and transportation costs Competing life activities Support groups

4.7 Knowledge regarding retention in care among HIV positive clients

4.7.1: Learning about the HIV diagnosis and where to access services

HIV testing and diagnosis is the entry point in HIV care cascade. Majority of participants knew where to be tested for HIV and most reported that they initially got to know their HIV status when a health care provider recommended it as they sought other services. Some participants learned their diagnosis while hospitalized with an opportunistic infection, such as Tuberculosis, or their partner were unwell or died. Few individuals sought HIV testing voluntarily. One participant stated:

“I was pregnant and went to seek antenatal care, was told one has to be tested for HIV because of the baby, I just accepted to be tested. It was in 2011” (FGD, female 35 years).

Retention in care is necessary if one has the full benefits of ART. Once they got to know their status most participants reported that the health care worker told them of where to seek services and a few were assisted by their family members to go to the clinic. Study respondents were aware of facilities to seek HIV related services with a majority of them reporting to have sought services in government supported facilities. Majority reported to have received good services from the same facilities. Few said they were dissatisfied with service. One respondent said:

“Am aware of government facilities like Mbagathi district hospital where I can pick my drugs if I cannot reach here or when I travel upcountry” (FGD, female 34 years)

4.7.2 Disclosure of HIV status

Lack of disclosure due to HIV related stigma was reported as one of the reasons why some patients discontinued care and follow-up after diagnosis. Most respondents said they were not always willing to disclose their status initially due to fear of how people especially family members will react. After disclosing their status they always get the challenge of discrimination because people have misconceptions and myths about HIV. As a result, patients opt to stop treatment which in itself affect adherence and long term retention. A participant said:

“At first it is always difficult to disclose because you imagine how people will talk about you” (FGD, male 42 years).

Stigma from community members was reported to be a barrier for retention of persons living positively into care while deterioration of health was a major enabler for HIV defaulters to re- seek HIV related services,

“People from the community fears us, discriminate and some even refuse to share cups and plates with us once we disclose our status but others encourages us” (FGD, male 30 years).

Despite this the health workers are humble and welcoming and they help us accept our status. We feel at peace at the health centers since we get warm treatment and encouraging words from the health workers.

‘‘The counselling they give us mainly is on how to build your self-esteem, acceptance of the your status and how to best to disclose and handle it’’ (FGD, female 36 years)

4.8 Perceptions and reasons for discontinuation of HIV care among HIV positive adults

4.8.1 Perceptions for discontinuing Care

The participants perceived that when one was doing better there is no need to come for scheduled visits. Most respondents said that follow up during pre-ART period seemed inappropriate because nothing much was done to them; except for the co-trimoxazole there was no other drug they were given. They mentioned that the long appointments they were given also contributed to them defaulting care. One participant said

‘‘I don’t see the reason for coming for a scheduled visit while when I come am told that am not yet eligible to start using the drugs and since am not sick I opt to stay at home’’ (FGD, female 22 years).

The respondents also said it depended on how one got the news about their status on the first day if it was in a polite and encouraging way or not. During this period of discounting follow up the respondents claimed their health deteriorated with time and had to go back to the health facilities.

4.8.2 Reasons for defaulting HIV care

When asked about reasons for missing scheduled visits, the respondents reported various reasons including; competing life activities such as attending a function upcountry like a burial, nursing a sick relative and getting time off work. One participant said

“I have missed my appointments twice when I had to travel upcountry to bury my mother and the other time my child had a school function which I could not miss” (FGD, female 40 years).

Some participants mentioned side effects as one of the reasons why some patients discontinue ART. Some of the side effects reported were fatigue, nausea, vomiting, and loss of weight around the pelvic region and abdominal distension. These may affect patient seeking behavior and may lead to attrition from ART care. One participant said:

“When someone is started on those drugs, he or she becomes weak due to tiredness and nausea so you stop taking them” (FGD, male 48years).

Few respondents reported that when they returned back to care, the treatment process was a long process hence you was discouraged to come back. A participant said:

“when you return back to care you wait for so long time to see a doctor because the process is tiresome and this discourages one and you drop out ” (FGD, female 32 years).

4.8.3 Relationship with the health care worker

All participants spoke highly of their health care workers in Pumwani clinic and said they were very caring to them. Some individuals mentioned that they depended on the health care workers for support, information and this helped them stay in care, one participant said:

‘we have confidence on health care workers of Pumwani because we trust them and this helps us to continue coming here for treatment’’ (FGD, male 56 years)

Some felt that the health care workers were truly attentive to their needs and that they offered support and the morale to live positively. One participant who recently lost her baby said:

‘‘When I lost my child after delivery, I was so stressed but thanks be to the support and encouragement I received from health care workers every visit I came to the clinic’’(FGD, female 33years).

4.9 Socio economic factors affecting retention in HIV care among HIV positive adults

4.9.1 Travel distance and transportation costs

Despite free ART services being offered in HIV clinics, travel distance and transport costs incurred traveling to the clinic may contribute to non-retention in care of patients on ART program especially more for patients who cannot afford it. Some participants reported travel distance to ART centers as a barrier to accessing treatment and some mentioned lack of money as a reason for defaulting.

‘‘Distance from home to the clinic is very long. I do not work so I cannot afford bus fare take one hour walking to this clinic when I am fast. I can even take up to two hours if am not fast. Sometimes, if am not feeling well, I cannot walk this distance and I don’t have someone I can send to come and collect the drugs for me, I miss the appointment date and come later when I feel better’’ (FGD, male 56 years)

4.9.2 Competing life activities

Other life activities which requires their attention were reported by most participants as a reason for missing appointments. Activities which were of top priority included: travel up

country for a burial, unable to get time off work and nursing a sick relative were some of the reasons mentioned which hindered attendance to scheduled appointments. One respondent said:

“According to me, the most challenging part is when I am supposed to come for an appointment and at the same time, I am supposed to be working so I end up not working on that day.” (FGD, female 44 years).

4.9.3 Role of support groups for HIV positive adults regarding retention in care

All the participants agreed that support groups; helped them adhere to ART, clinic appointments and offered an opportunity to encourage one another to be continuously engaged in care. One participant said:

“Support groups help us a lot to accept our status, take drugs well and you make friends who help you to remember your appointment dates (FGD, female 32 years)

All participants agreed that counselling and health education offered by the health workers routinely helped them to be informed about the importance of taking drugs and staying in care. They also suggested they should have counselling more often to encourage the issue of follow up. For those traced back into care, it was reported that they were satisfied and content with the services they received as they understood the reasons why they should continue in HIV care as a result of counselling when they joined a support group where they found other people who encouraged them to stay in care.

CHAPTER FIVE

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion

5.1.1 Socio demographic factors associated with retention in HIV care

This study findings shows that, 73.5% women are retained in care compared to men (26.5%). The high proportion of women in care is attributed to the many avenues such as maternal health clinics where women seek various health services pertaining to their health and while seeking these services the HCW offers HIV counselling and testing as a package of care in line with other health services. This offers an opportunity for health education on the benefits of treatment and being retained in care leading to earlier identification and timely linkage to care. High proportion of women retained in HIV care was also observed by (Babatunde et al., 2015; Tiruneh et al., 2016) in Nigeria and in Ethiopia where 68.6% and 64.4% were women respectively. Retention of more women in care than men after ART initiation, may reflect gender differences in health seeking behavior which has been shown to affect retention in care in other resource-limited countries (Brinkhof et al., 2008) and male sex has been associated with loss to follow up in care (Alamo et al., 2012; Stolka et al., 2016). This leads to poor retention in care which translates to poor survival rates as they seek care when they have opportunistic infections which has a negative impact on survival (Giordano et al., 2007).

Study findings found out that, 62% participants retained were married. Individuals who are married individuals not only offer mutual social support to one another but they also help each other adhere to ARVs and clinical appointments. Higher retention among married participants was also evidenced by a studies conducted in Ethiopia (Tiruneh et al., 2016; Byakika-Tusiime et al., 2005) at three treatment centers in Kampala Uganda.

Clinical appointments in Kenya are scheduled to coincide with refill of ART (NASCO, 2011). Hence adherence to scheduled clinic appointments translates to good adherence to

ART as we are able to monitor the progress of a client and refill prescriptions. Thus good adherence to ART among married persons may be a positive predictor of adherence to ART which translates to being retained in care and positive health outcomes. Further research is probably needed to gain more insight into the influence of marital status on adherence to ART and retention in care.

The age group retained in care most for this study was between 35-44 years (39.9%) and 18-24(4.7%). Poor adherence to ART and retention in HIV care among the young adults is associated with stigma, peer pressure, challenges of disclosure and the transition they are undergoing in their various stages of their lives. Results from other studies have shown age is a basic factor in keeping participants in HIV care, in that older patients are more likely to stay in care because they have broad knowledge about the care which helps them to really grasp the necessity and benefits of being retained in care (Yehia, Stephens-Shields, et al., 2015). Younger age has been associated with missed clinic visits leading to poor retention in care translating to higher risk of morbidity and mortality as they are not monitored routinely (Mugavero et al., 2010). Age has been found to have an influence on adherence to ART as (Hinkin et al., 2004) found out older patients revealed significantly better medication adherence than younger patients (87.5% versus 78.3%). As barriers to adherence and retention in care overlap, young HIV infected persons with poor adherence to medications are poorly retained.

Literacy levels was average in this study for those retained; 45.7% had primary and lower level of education while 54.3% had attained secondary or tertiary level of education. This finding could be attributed to the fact that education helps clients to appreciate the basics of HIV teaching, importance of continuously engaging in care and doing all it takes to be retained in care. Various studies have found that there is a relationship between retention, adherence and level of education. A study conducted in Ethiopia found out having a lower level of education was marginally associated with being LTFU when compared with those with secondary and above education (Tiruneh et al., 2016). Education has been found to assist a client adhere well to ARVs and subsequently be retained in care. In a cross-sectional study of 366 patients in Spain, subjects with a low level of education had the

worst adherence while those with a university degree had the best (Gordillo, Soriano, & González-lahoz, 1999). A notable fact in this study was the complexity of regimens which required the patients to take more pills per day often with dietary restrictions. A higher level of education would make it easier to understand the importance of retention in care and being able to navigate a lifelong complex condition.

5.1.2 Proportion of retention in HIV care

The proportion of retention in care in this study was 66.8% for clients who had been in care and had been on follow-up for a period between six and sixty months. (Enrolled from January 2010 to December 2015).

Retention rates has been found to decrease with years of enrollment because more people live the program due to various reasons ranging from; death, change in location, feeling of wellness after viral suppression, improved conditions of health or other economic and religious factors, especially in Africa (Babatunde et al., 2015). The overall retention rate falls slightly lower when compared to a study conducted in Sub Saharan Africa by (Rosen et al., 2007) which shows, overall retention in ART programs 60 months after initiating patients on treatment averaged roughly 70% using a random effects meta-analysis of reported results. Maintaining PLHIV in the lifelong care is one of the key elements of the World Health Organization and United Nations Program on HIV/AIDS strategy towards achieving universal access to treatment for PLHIV (UNAIDS, 2014). In order to achieve the goal of viral suppression for all PLHIV, retention in HIV patients is essential. It provides an opportunity for PLHIV to benefit from HIV care and treatment as they complete sequential steps from HIV testing and diagnosis, linkage and retention in care, initiation and adherence to ART (Fleishman et al., 2012).

Retention in care is also critical in monitoring response to HIV therapy, to offer and deliver prevention services and social support (Fleishman et al., 2012). It improves survival and reduces risk of HIV transmission but LTFU poses a challenge to this as it increases risk of morbidity and mortality (Cornell et al., 2014; Geng et al., 2010).

5.1.3 Knowledge and perceptions regarding retention in HIV care

Knowledge of where to be diagnosed for HIV is the first step in the care cascade, providing an opportunity for linkage to care and early management of HIV. This study results showed that the participants who knew that HIV testing is offered by a provider through PITC were significantly two times higher to be retained in care than those engaged in VCT. The same was also seen in the focus group where majority of participants reported that they initially got to know their HIV status when a health care provider recommended it as they sought other services. This is attributed to the adherence and importance of being in care emphasized by the provider during the testing and counselling such as; to be cured of the opportunistic infection or to have a HIV negative child, thus preferring to be retained in care.

Testing initiated by a provider is beneficial as it identifies patients earlier before their immunity is compromised. Late identification of HIV positive individuals has been demonstrated by prior studies that it leads to patients initiating ART late, with very low CD4 counts and risk of death is high (Brinkhof et al., 2008) while those who survive, suffer more morbidity and utilize more medical care resources than would otherwise have been necessary (Leisegang et al., 2009).

Study findings depicted 82.5% of participants retained in care were aware that they should be enrolled in HIV care after diagnosis within three months. Successful linkage to care after diagnosis is important for a person who is HIV positive because of the negative consequences of late presentation for treatment. Delayed entry into care increases chance of poor survival for PLHIV due to risk of infections which may lead to death and this negatively affects retention (Giordano et al., 2007). Patients lost before enrollment mainly risk becoming late presenters to treatment as they maybe asymptomatic and may not perceive themselves as not requiring medical care (Rosen & Fox, 2011). This poses a risk to the fight of HIV/AIDS because lost to care patients not enrolled in HIV care are sources of new (Cohen et al., 2011). Linkage of these clients in care is significant not only in reducing AIDS related mortality but also preventing new infections.

Study participants (85%) retained in care were aware of other facilities in which they could access ARVs and other services if they could not reach the clinic on their appointment day. Knowledge of where to receive ART services in case one cannot attend their scheduled appointment is vital in the continuity of care for HIV infected persons. Retention in care includes transfers while retention in facility does not. The undocumented movement of clients and its consequences on efficient use of limited resources present a challenge to delivery programs and retention in care (Ochieng Ooko et al.; 2010). This is because when a client misses an appointment they are deemed as a defaulter. Tracking of patients is one way of monitoring retention among patients in HIV treatment programs as a client may have missed an appointment yet they refilled their ARVs at a another facility. It is important to note that meaningful outcomes affecting retention in HIV care, hidden by LTFU, include deaths prior to ART initiation; silent transfers (including possibly ART initiation at new sites); and disengagement from care with failure to start ART (Thomson, Cheti, & Reid, 2011).

About 71% of study participants retained in care; were aware that they were to see a HCW at least four times in a year. After the commencement of ART, there is the need for continuous monitoring and counseling to achieve and achieve and maintain viral suppression. This ensures that the individual obtains the full benefits from the treatments. Attendance to the clinic appointments is proxy to retention and prescription refills are arranged to coincide with clinic appointments in Kenya (NASCO, 2011). Patients on ART that miss their appointments are more likely to miss their doses and this affects their health and are poorly retained in care. Continuous engagement in HIV care has been associated with better health outcomes for PLHIV (Cohen et al., 2011) and the general population as a whole (Das et al., 2010; Montaner et al., 2010). While not being in care or consistent care may contribute to poor health outcomes (Crawford, 2014) increased mortality (Mugavero et al., 2010) and a large percentage of new HIV infections (Skarbinski et al., 2015).

This study found out that 89.7% of the study participants had disclosed and they received support to continuously engage in care. Disclosure of HIV status to family and friends can ease the burden of taking a lifelong medication, but patients also fear that disclosure may lead to hostility or rejection (Medley, & S., 2004). Disclosure of HIV status has been found to assist in retaining a client in care and improves the general wellbeing of the client because of the support given by family members or friends. It has been found to be helpful in fighting stigma, reducing the work involved in preventing unintentional disclosures, establishing a community in which to share ideas, and obtaining resources (WHO, 2011; Yehia, Stephens-Shields, et al., 2015). The support from family is important as it prevents LTFU which significantly affects retention in care. A study done in Tanzania revealed that 5% of respondents were LTFU due to the lack of support from the family. Lack of knowledge on how to manage HIV disease amongst family members is attributed to the lack of disclosure by participants because if they disclose their HIV status they tend to be stigmatized and isolated hence fail to get support on treatment leading to LTFU (Salema, 2015). Lack of support from family and community leads to clients dropping out of care hence are LTFU and this translates to poor retention and poor survival rates (Bwirire et al., 2008; Kagee et al., 2011).

Study participants' perception of retention of HCW was positive where 69.5% of clients retained perceived HCW as being good. Also this was resonated by the participants in the Focus group interviews who spoke highly of their health care workers as being compassionate to them. Supportive relationships between patients and health care provider builds trust and the patients finds it easier to follow the provider's recommendations and advice. This was observed by a qualitative study which found out that positive relationships with clinic staff including the HIV providers was one of the most commonly discussed facilitator to retention in care. Furthermore, having a meaningful relationship creates a sense of trust, allowing patients to honestly share all their experiences regarding health and adherence behaviors. It is reported that patients enjoy coming to the clinic where they feel supported by clinic staff (Yehia, Stephens-Shields, et al., 2015). Satisfaction with the clinic experience and relationship with the staff

predicts whether or not patients return for care (Salisbury, Wallace, & Montgomery, 2010) and is positively associated with retention in care and adherence to ART (Dang, Westbrook, Black, Rodriguez-Barradas, & Giordano, 2013).

5.2 Factors associated with retention in care among HIV positive adults

5.2.1 Adherence to scheduled clinic appointment

This study found out that most participants retained preferred to be reminded to attend a scheduled clinic appointment by use of an appointment card (70.3%) and text message service (69.4%). This helps to improve retention in care as a client will not miss their appointments; in event they cannot make it they are able to reschedule. This agrees with an adherence study conducted in Kenya by (Lester et al., 2010) which found out that patients who received Short message service support had significantly improved their adherence to clinic appointments leading to improved ART adherence and rates of viral suppression compared with the control individuals.

The study findings showed that the appointment waiting time in the clinic contribute to retention. Of those clients retained, 79.4% reported to spend less than two hours to receive services from the time they present their card to the point they receive drugs and exit with 83.8% saying that the time was adequate. Long queuing duration has been associated with the LTFU among HIV positive adults who attend care and treatment clinic (Salema, 2015). Lost to follow-up translates to poor retention for PLHIV and since there outcomes are not known and they are at risk of transmitting new infections, risk of morbidity and mortality.

5.2.2 Competing life activities and stigma

More than half of study participants (53.6%) who reported to have ever missed a scheduled appointment reported that competing life activities followed by stigma hindered them from attending to their clinic visit. Failure to attend the clinic as scheduled means lack of refill of ARVs and monitoring for drug toxicity, clinical HIV progression, diagnose and treat new opportunistic infections and other concurrent diseases that may occur (Patel et

al., 2010). Prior studies noted that regular attendance at clinic is not always the top priority for some participants and the common challenges they face are: caring for children or elderly family members, work, and school (Fleishman et al., 2012). Competing demands for scarce resources and unanticipated obligations such as attending a family funeral are key adherence barriers acknowledged that have an effect on retention in HIV care (Tuller et al., 2010). Attending clinic is key in the HIV treatment cascade and proxy to retention (KAIS, 2012). Thus, missed appointment translates to poor retention and poor outcomes

Stigma (13.3%) was another reason reported by participants as a barrier to attendance to clinic appointments. Many participants reported hesitancy to disclose their status to family, friends, and acquaintances. HIV positive patients drop out of care because they do not want to be seen in the HIV clinic and risk chances of being seen by someone they know. This stigma and discrimination could cost their social relations, business openings and their chance of living in harmony with people in their surroundings. According to some FGD participants, people do not disclose their status even to their close family members (including spouse and children) which forces them to stop from going to health facility in order to keep the secret. This finding is consistent with other studies that identified HIV related stigmas to be an important barrier to adherence and retention in care (Merten et al., 2010).

Uncertainty about how family, friends, or the public would respond to their status made some patients anxious and affected their ability to attend appointments and these participants said it is a barrier to continuous engagement on care (Govindasamy, Ford, & Kranzer, 2012). This means client drop out of care because of fear of disclosure and the perceived stigma hence miss their drugs and are at risk of getting infections.

5.2.3 Travel distance and transportation to the clinic

This study found out that participants retained (44.4%) live within hospital proximity and they do not use bus fare to reach the clinic, whereas those living far and spend bus fare only 7.7% are retained in care. Cost of transportation to and from health facility during follow up visits is a factor that has been identified with poor retention. Although HIV treatment is freely available to all in Kenya, most participants in the FGD mentioned that the cost of transportation during each visit is hindering some of them from attending their care regularly subsequently affecting retention in HIV care.

This was observed by a study conducted in South Africa that found out factors associated with higher rates of lost to follow up was clients living ≥ 10 km from the health center (Losina et al., 2010). Travel distance to clinic sites and associated costs have been described as obstacles to retention (Tuller et al., 2010) and perceived reason for the high loss in care (Mulissa et al., 2010). Failure to attend clinic means one is not monitored routinely which is accepted as a cornerstone of HIV disease management (WHO, 2011). The implications of chronic LTFU and unstructured ART interruption include increased risk of treatment failure, infections which may lead to death (Kranzer & Ford, 2011).

5.2.4 Use of Antiretroviral drugs

This study found out that clients on ARVs are four times likely to be retained in care compared to those not on ARVS (OR: 3.965; 95%CI [1.632-9.733]; p-value <0.001). This is attributed to the fact that clients on ART require frequent visits to the health care worker for routine monitoring. Previous studies have observed that clients not on ART are at higher risk of stopping and defaulting from care as compared to patients on ART (Ahonkhai et al., 2012; Alamo et al., 2012) and end up being LTFU during the Pre-ART period (Fox & Rosen, 2010; Pati, Lahuerta, Elul, Okamura, Alvim, Schackman, Bang, Fernandes, Assan, Lima, et al., 2013)) as most are asymptomatic during this period.

Though earlier studies attribute large numbers of LTFU of ART patients to early mortality (Pati, Lahuerta, Elul, Okamura, Alvim, Schackman, Bang, Fernandes, Assan, Lima, et al., 2013), patients who are not eligible for ART are less likely to have died (Lessells, Mutevedzi, Cooke, & Newell, 2011). However, they remain at risk of late ART initiation (Nash, Wu, Elul, Hoos, & El Sadr, 2011) and as a result, increased risk of early mortality after starting ART (Lawn, Myer, Orrell, Bekker, & Wood, 2010; Ndiaye et al., 2009). In addition, pre-ART patients who are neither engaged in care nor on ART are more likely to transmit HIV to sex partners than those who engage in care and initiate early ART (Cohen et al., 2011). This undermines the prevention efforts and the global fight of HIV to lower morbidity and mortality among PLHIV. The finding that never initiating ART was associated with higher chances of being LTFU call for strategies that enable earlier initiation of ART and promote retention in care (Clouse et al., 2013).

5.2.5 Lost to follow up among HIV positive adults

This Study found out that 34.3% were LTFU for three to six months and 36.2% for more than six months. The critical problem with LTFU patients is that such individuals are not ART naïve. The more the number of such patients, the more the opportunities for development and transmission of drug-resistant strains of HIV in the community (Fleishman et al., 2012).

Disengagement from care affects retention in care significantly and translates to poor survival rates for persons LTFU and costs implications for the program in tracing the clients. Having a high number of clients LTFU costs the program in tracing them back for treatment. This has been evidenced by a study done in Johannesburg on the cost of using patient tracer to reduce the loss of follow up visits among clients attending at care and treatment Centre (Rosen & Ketlhapile, 2010).

Missed clinic visits leads to LTFU if clients are not traced back to HIV care; these missed visits may be attributed to missed opportunities for monitoring non communicable diseases such as psychiatric illness, hepatitis C, diabetes, or heart disease, alcohol, drug

and substance abuse, in addition to missed chances for ART and prophylaxis against opportunistic infections and this contributes to increased morbidity and mortality. Provider continuity has been demonstrated to be important in general medical care because the provider gives objective support for HIV treatment to the patients hence need to be seen every 3–4 months while receiving ART (KAIS, 2012).

Study findings also showed that more than half of those clients with history of LTFU were not on ARVs and in good health and asymptomatic (65.2%). This builds up to prior studies which demonstrate that Pre-ART period contributes to LTFU as most clients are asymptomatic hence do not feel the need to be followed up. They wait till they became sick to return to care. This is attributed to the fact that ART clients have a treatment plan laid out and routine adherence counselling that is done at every visit unlike Pre-ART patients who are likely to require less frequent follow-up visits as most often they feel well and are asymptomatic (Mulissa et al., 2010; Pati, Lahuerta, Elul, Okamura, Alvim, Schackman, Bang, Fernandes, Assan, & Lima, 2013; Robi, 2013). Directing our efforts on patient retention in care both before and after ART initiation is important not only to prevent HIV related mortality and morbidities, but also as a means of reducing ongoing transmissions which will reduce the number of new infections. Patients who drop out of care at this stage usually either come back after the disease has advanced as late presenters or die even before that. Pre-ART care is thus a vital link in the chain that connects HIV positive patients to the desired lifelong treatment (Robi, 2013).

5.2.6 Tracing of Lost HIV positives adults from care

It is possible that many patients who drop out of care will return to care at some later date either through tracing or when they become sick. This study revealed that tracing of clients is essential in retaining clients in care. Clients who returned to care (42.5%) reported to have been traced by a health care worker while 13.8% were sick. Lack of an effective health system tracking that allows patients to be followed from site-to-site and over time, as they come and go from care, leads to difficulty in monitoring the extent to which patients are cared for through referral structures.

In view of the fact that literature suggests high rates of early mortality after ART initiation in Africa (Lawn, Harries, Anglaret, Myer, & Wood, 2009; Losina et al., 2010), it is plausible that recently diagnosed HIV-infected clients register for care and dropout while they are still healthy, only to present later with advanced HIV disease necessitating immediate ART initiation. In fact a significant number of them die at home not captured by the healthcare system. This significantly affects HIV prevention efforts as these patients will have continued to transmit HIV virus to loved ones or any other sexual contact during the time he/she has been lost-to-follow up. Thus retaining clients in care has potential effect not only in reducing AIDS related mortality but also preventing new infections (Cohen et al., 2011).

Active defaulter tracing of clients as soon as they miss their appointments contributes to a reduction in LTFU. Tracing of patients has been found to have benefits both to the client and program leading to improved retention as barriers to clinic attendance are identified and mitigated (Thomson et al., 2011). This calls for programs to have strategies, mechanisms and policies on how to actively trace defaulters and LTFU clients if retention in care and the ultimate goal of viral suppression among PLHIV on ART is to be achieved.

5.3 Conclusion

1. In this study, only 66.8% of participants were retained in care. More women are retained in care compared to men.
2. The participants have knowledge regarding retention in HIV care and there is a significant relationship between clients who knew they could be diagnosed through PITC and retention in HIV care
3. There is no significant relationship between perceptions regarding retention in HIV care and retention in care
4. There is significant relationship between clients on ARVs and retention in HIV care
5. There is no significant relationship between factors such as appointment keeping, transportation costs and lost to follow-up and retention in HIV care

6. Competing life activities affects one's ability to adhere to scheduled clinic appointments.

5.4 Recommendations

1. Benefits of retention in HIV care should be emphasized on by health care workers to ensure increase in retention rates
2. HIV positive individuals have high knowledge on the frequency of seeing a health care worker and where to receive HIV services hence, dissemination should continue
3. Early identification of HIV infected persons through provider initiated testing and counselling with strong linkages to care and active tracking; ensures successful linkage and long term retention in care.
4. ART is essential in retaining a client to care. Interventions such as counselling should be initiated early and done routinely during the entire period of treatment.
5. Implementation of community based ART distribution models to stable HIV positive individuals, to improve retention in care and lower missed clinic appointments chances
6. There is need for the Ministry of Health and Nairobi county government to have a policy of lost to follow-up which tracks patients who are not adhering to clinics as scheduled.

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APPENDICES

Appendix 1: Questionnaire.

Study title: Factors associated with retention in care among HIV Positive adults attending Pumwani Care and Treatment Clinic in Kamukunji sub county, Nairobi

Investigators: J.Ronoh, Dr Mutisya Kyalo, Dr Joseph Mutai

Questionnaire no

Client's unique number: _____ Clinic Name: _____ Date of interview: _____

Socio demographic data

1. Gender 1.1 Male 1.2 Female
2. 2.1 Age _____ 2.2 Year of Birth _____
3. Marital Status
 - 3.1 Single
 - 3.2 Married
 - 3.3 Divorced
 - 3.4 separated
 - 3.5 widowed
4. Level of Education
 - 4.1 None
 - 4.2 Primary
 - 4.3 Secondary
 - 4.4 College
 - 4.5 University

5. What is occupation?

5.1 Employed

5.2 Self-employed

5.3 Unemployed

5.4 Casual

6. What is your income per month?(Ksh.)

6.1 <1000

6.2 1,000 – 5,000

6.3 5,001 –10,000

6.4 10,001- 20,000

6.5 > 20,000

Knowledge and Perception

7. What prompted you to be tested for HIV first time? (Knowledge of entry point)

7.1 Was sick and or a doctor recommended (PITC)

7.2 Just wanted to know my status (VCT)

8. How long did you wait to enroll into care and treatment program after you were diagnosed with HIV?

8.1 Was enrolled immediately

8.2 Less than a week

8.3 1-4 weeks

8.4 1-3 Months

8.5 >three months

9. Have you disclosed your HIV status to anyone?

9.1 Yes

9.2 No one (skip to question 11)

10. How have they been supportive of you seeking care?

10.1 Remind me to take drugs

10.2 Accompany me to hospital

10.3 Financial support

10.4 Remind me to attend my appointments

10.5 social support

11. Why have you not disclosed to any one?

11.1 I'm afraid to be stigmatized and discriminated

11.2 I'm afraid to be divorced

11.3 I'm afraid to lose my job

11.4 No reason

12. Have you been counseled on the dangers of missing your appointments, care and treatment?

12.1 Yes 12.2 No

13. Were you informed of where to go for treatment and care in case you cannot access the facility?

13.1 Yes 13.2 No

14. Have you ever sought care and treatment services from another facility apart from the one you are enrolled in?

14.1 Yes 14.2 No (skip question 16)

15. If yes, what services were seeking?

15.1 Treatment

15.2 Refill (ARVs/Septrin)

15.3 Lab tests

16. How frequent are you supposed to see a health care worker in a year?

16.1 Once

16.2 Twice

16.3 Thrice

16.4 Four times

16.5 More than four times

17. What is your view towards health workers in Pumwani Clinic?

17.1 Good

17.2 Average

17.3 They stigmatize other clients

18. Do you think the time for the Pumwani clinic services is enough?

18.1 Yes

18.2 No

19. Do you think missing clinic appointments puts your health at risk?

19.2 Yes

19.3 no

20. How do you prefer to be followed up and reminded to attend your scheduled clinic appointments? (Tick as appropriate)

20.1 Phone call

20.2 SMS (short message service)

20.3 Home visit/home based care

20.4 Treatment buddy

20.5 None

Factors associated with retention in care

21. How many hours do you take to reach Pumwani Clinic?

21.1 < 30 mins

21.2 One hour

21.3 Two hours

21.4 >

Three hours

22. How much did you spend for transport to Pumwani Clinic? (In Ksh)

22.1 < 100

22.2 101-500

22.3 500-1000

22.4 >1,000

23. How long do you take to be attended to in Pumwani Clinic?

23.1 < 30 Mins 23.2 1 – 2 Hours 23.3 2 – 3 Hours 23.4 > 3 Hours

24. How do you comment on time you spend in Pumwani clinic?

24.1 Short 24.2 Average 24.3 Long 24.4 too long

25. Have you ever missed clinic for any reason?

25.1 Yes 25.2 No

26. If yes, what made you missed your clinic appointments?

26.1 Lack of transport fare

26.2 Stigma

26.3 Afraid of side effects

26.4 Lack of support

26.5 Was not happy with services in this clinic

26.6 Decided to shift to another clinic

26.7 I could not get time off from work

27. How many times have you missed your clinic appointments?

27.1 Once 27.2 Twice 27.3 Thrice 27.4 > Thrice

28. For how long did you stop being followed up in care and treatment?

28.1 < 3 Months 28.2 3 Months 28.3 6 – 12 Months 28.3 > 12 Months

29. How was your health during this period you were lost to follow up/break?

29.1 I was well/Not sick

29.2 I was well initially but later got sick

29.3 was always sickly

30. Were you on ARVs when you missed your clinic appointments?

30.1 Yes 30.2 No

31. Where were accessing your ARVs

31.1 I missed taking them

31.2 Picked at another facility

31.3 I borrowed from spouse/friend/relative

32. What brought you back to the clinic?

32.1 I was followed up

32.2 Was counseled by a friend

32.3 I accepted my status and decided to come back

32.4 I was sick

Thank you for your time and participation

Appendix 2: Informed consent Form

Informed consent Form

Study title: Factors associated with retention in care among HIV Positive adults attending Pumwani Care and Treatment Clinic in Kamukunji sub county, Nairobi

Hello, my name is Judith C.Ronoh and I am student at the Jomo Kenyatta University of Agriculture and technology (JKUAT). I am conducting a study on Factors associated with retention in care amongst HIV Positive adults attending Pumwani Care and Treatment Clinic in Kamukunji sub county, Nairobi. I would like to seek your permission to participate in this study, please read the consent form below.

Introduction and Purpose of the Study

This study seeks to assess proportion of retention, knowledge, attitudes, perceptions and factors associated with retention in care among LTFU HIV positive clients in order to help find ways that would improve retention in care amongst them and entire program.

Procedure

If you agree to take part in this study, you will be asked to fill in a questionnaire with the help of a trained health care worker. And some will participate in the focus group discussion. Focus discussion groups will have about 8-12 people who get together and discuss their ideas and thoughts about important issues. The discussions will be led by a member of our research staff and an independent facilitator.

Risks

We do not anticipate that participation in this study will pose physical or psychological risks beyond what you encounter in everyday life. However, Participation in this study is voluntary and if you are uncomfortable answering a particular question, you are free to

not to answer the question, and you are free to leave the study at any time. You will not receive any payment to participate in the study.

Benefits

The information you provide to the investigator will shed light on the factors associated with retention in care amongst HIV Positive adults, and the study results will assist us in informing PLHIV, representatives of Pumwani CCC and other stakeholders to help improve retention among PLHIV and develop suitable strategies.

Other Information

Any information given to the study will be kept private. Your name will not be used in any report coming from this study. The questionnaires and the consent form will be safely kept where only the study staff may have access to the information. The information collected will remain confidential. All research material will be submitted to JKUAT for official documentation purpose.

In case you have any questions you can contact the investigator Judith Ronoh on 0722-756748 or supervisors; Dr Kyalo on 0721 -484869, Dr Mutai on 0725-082352 or KNH-UoN/ERC Secretary Contact telephone numbers 2726300 ext 44102, email uonknh_erc@uonbi.ac.ke.

Your signature below shows that you understand the above statement and willingly agree to participate in the study.

This consent form has been read and explained to me. I voluntarily consent to participate in this study:

Signature: _____ Date: _____

(Study participant)

I have explained the study for the above subject and I have sought his/her understanding for informed consent

Signature: _____ Date: _____

(Research assistant)

THANK YOU FOR YOUR TIME AND PARTICIPTION

Appendix 3: Focus group discussion guide

Focus group discussion (FGD) guide

Subject Information Sheet/ Verbal Consent

Introductions:

1. Thank participants for their willingness to participate on the FGD
2. Introduce facilitators and explain their role
3. Describe the detail of FGD using the following information:

Hello, my name is Judith C.Ronoh and I am Masters Student at the Jomo Kenyatta University of Agriculture and technology (JKUAT). I am conducting a study to find out if HIV positive clients have knowledge on retention in care, and their attitudes, perceptions and challenges encountered.

The study aims to gather this information and help address issues affecting retention in care. We are looking forward to hearing your experiences and learn from you and your peers. To gather this information a focus group discussions is being carried out. We are asking if you will be willing to participate in one of these group discussions and share your views. The information you provide will be used to assess PLHIVs knowledge, attitudes, opinions about HIV care and barriers to clinic appointments. The final results will be shared with representatives of Pumwani CCC and concerned community groups to help improve care for patients during to ensure successful continuous engagement.

Focus discussion groups have about 8-12 people who get together and discuss their ideas and thoughts about important issues. The discussions are led by a member of our research staff and an independent facilitator. Your responses, opinions and ideas are very important to this project.

During a focus group discussion, you are allowed to talk freely and spontaneously everything you know about issues that your facilitator will raise concerning retention in care. We will tape record the session and a transcript will be made. By consenting to participate in the study, you are agreeing to the tape recording of the session. Please do not use any names when you share. We will not use any names when writing our reports. The session will last approximately 1.5 hours to complete. As every one's ideas are highly valid, you are kindly asked to actively participate, listen to each other, and respect each other's opinion. It is not allowed to criticize others' idea during the FGD and even outside.

We do not anticipate that participation in this study will pose physical or psychological risks beyond what you encounter in everyday life. However, you may not feel comfortable answering some questions in front of your peers. You have the right to refuse to answer any question that you do not wish to answer. Also, you can choose to leave the discussion at any time. You do not have to participate if you do not want to but this will not affect your chances of ever joining or using the services provided through the program. The benefit to you is that you will be sharing your opinions and experiences that will help improve retention in care and other services provided in the care and treatment program.

The information collected will remain confidential. This means that your identity as a participant and the information that you will provide will not be revealed to people other than the study facilitators. We are not taking your name and address during the discussion. All audio recordings will be erased upon completing the study. We will keep all sensitive files, notes, and interview tapes password protected or in locked cabinets. If the results of the research are published, neither your name nor personal identifying characteristics or those of anyone else in the study groups will be revealed.

- Do you have any questions?
- Do you agree to participate in the focus group discussion? If you do not want to participate, you may leave the room at this time.

FOCUS GROUP FACILITATOR:

You must sign below before proceeding. Your signature certifies that the objectives and procedures of this study have been read to the focus group participants. It also certifies that you have answered all the questions that the respondents m had about the study and that each participant remaining in the room has voluntarily agreed to take part in the research. _____

Date

Signature of Focus Group Facilitator

FGD Participants' Basic Information

FGD Session Number Facilitator Date place

Participant's code	Q1 Sex <input type="checkbox"/> Female <input type="checkbox"/> Male	Q2 Age <input type="checkbox"/> 18 to 25 years <input type="checkbox"/> 26 to 35 years <input type="checkbox"/> 36 to 40 years <input type="checkbox"/> 41 to 45 years <input type="checkbox"/> 46 to 50 years <input type="checkbox"/> 50 and above	Q3 Education <input type="checkbox"/> None <input type="checkbox"/> Primary <input type="checkbox"/> secondary <input type="checkbox"/> College <input type="checkbox"/> university	Q4 occupation <input type="checkbox"/> employed <input type="checkbox"/> Self-employed <input type="checkbox"/> unemployed <input type="checkbox"/> Student <input type="checkbox"/> Other
P1				
P2				
P3				
P4				
P5				
P6				
P7				
P8				

QUESTIONS

Experience with care and treatment

1. How do people get enrolled into HIV care and treatment? (Probe on: From whom/where people get the information about the program? Where do people usually seek (care) the first time they know they are HIV positive? Who assist in their decision?)
2. Do you know of other places you can access HIV care and treatment services from, apart from our facility?
3. How do people like you describe their experience in care and treatment? (Probe on: type of services, for how long, follow-up period, counseling, its benefits)
4. Do people on care inform their families about them being on the HIV program? Why and why not? What support is available in the community, in the family, in the workplace? (Probe on: care and support services, discrimination, and stigma.)
5. How do you think you are being treated (handled) by the health workers while you have returned to care? (Probe on: in relation to privacy, confidentiality, respect, being listened to, time spent with patient, waiting time, integration with other services,)
6. What does the counseling provided as part follow up in Pumwani clinic entail?

Reasons for discontinuation

7. Why do people discontinue follow up?
8. What do they do after discontinuation of care and treatment? (Probe on: treatment options.)
9. How is their health during this period you missed coming to the clinic?
10. How does health situation of people who discontinue care compared before and after discontinuation?
11. When one is lost to follow up do these people want to restart on their care and treatment?
12. What needs to happen for these people to restart?

13. What do you think could be done to help people like you to continuously follow their appointments?

Individual and social influences/barriers to retention in care

14. Do people enrolled in HIV care clinic face any socioeconomic and other problems because of their medical condition? (Probe on: poverty, hunger, transport problems, lack of support)
15. How does the community view people who are HIV positive? (Probe on: stigma, discrimination, supportive attitude, negative attitude, etc.)
16. What should be done to ensure that those PLHIV are retained on Care?

Conclusion remark

Thank you very much for your cooperation and input.

Appendix 4: Kenyatta National Hospital/ University of Nairobi ethical approval form



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Ref: KNH-ERC/AM433

Judith Chemutai Ronoh
TM310-3155/2015
School of Public Health
JKUAT

Dear Judith

REVISED RESEARCH PROPOSAL; FACTORS ASSOCIATED WITH RETENTION IN CARE AMONG HIV POSITIVE ADULTS ATTENDING PLUMWANI COMPREHENSIVE CARE CENTRE IN NAIROBI COUNTY, KENYA (P623/08/2016)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above revised proposal. The approval period is from 4th November 2016- 3rd November 2017.

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 serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- 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 hours.
- 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 ERC 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.

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4th November 2016

For more details consult the KNH- UoN ERC website <http://www.erc.uonbi.ac.ke>

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 Chairperson, KNH- UoN ERC
The Assistant Director, Health Information, KNH
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