FACTORS ASSOCIATED WITH LOSS TO FOLLOW UP OF HIV PATIENTS LIVING WITH HIV IN KIAMBU COUNTY REFERRAL HOSPITAL

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Factors Associated with Loss to Follow Up of HIV Patients Living with HIV in Kiambu County Referral Hospital

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DECLARATION

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

Signature……Date……

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This thesis has been submitted for examination with our approval as university supervisors:-

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Signature……Date……

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DEDICATION

This work is dedicated to my family: David, Aimie and Nathan as a reminder of hard work through challenging times and unrelenting spirit of success and victory.

ACKNOWLEDGEMENT

I would like to acknowledge the Almighty God for giving me the Grace and provision to undertake this course.

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ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ALT	Alanine transaminase
ART	Antiretroviral Therapy
ARV	Antiretroviral
AUD	Alcohol Use Disorder
CCC	Comprehensive Care Clinic
CTX	Cotrimoxazole
DNA	Deoxyribonucleic Acid
DRC	Democratic Republic of Congo
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
KAIS	Kenya AIDS Indicator Survey
KAIS	Kenya Aids Indicator Survey
KCRH	Kiambu County Referral Hospital
LTFU	Lost to Follow Up
NASCOP	National AIDS and STIs Control Program
NNRTI	Non-nucleoside reverse transcriptase inhibitor
OGAC	Office of Global AIDS Coordinator

PMTCT	Preventing Mother-to-Child Transmission
RNA	Ribonucleic Acid
UNAIDS	United Nations Agency for International Development
USAID	United States Agency for International Development
WHO	World Health Organization

DEFINITION OF TERMS

Treatment supporter/Buddy This is a friend or family member who helps the patient to take medications regularly—reminding the patient to take his/her medication on time, offering encouragement to keep going, helping to keep hospital appointments and providing support (Population Council, 2006).

Loss to follow Up This refers to a patient who has not responded to at least three follow-up contacts after three months (90 days) of not being seen by a health worker (WHO, 2018).

In Kiambu County Referral Hospital, one becomes a lost to follow up 90 days of not attending a scheduled clinic appointment.

Defaulter A patient engaged in HIV care and treatment who misses a clinical appointment or fails to collect their antiretroviral drugs from the HIV clinic for at least seven days (NASCOP, 2014)

ART Medication Adherence Medication adherence is defined as taking all medications at the appropriate time with the appropriate dosage as prescribed by the physician (Alakija *et al*., 2010)

Adherence to HIV care and treatment It refers to the whole process from choosing, starting, managing to maintaining a given therapeutic medication regimen to control HIV viral replication and improve function of the immune system (Alakija *et al*., 2010).

Non-adherence is the discontinuity or cessation of part or all of the HIV care and treatment such as dose missing, underdoing, or overdosing, clinic attendance and drug holidays (Alakija *et al*., 2010).

Retention in HIV Medical Care (Continuous HIV Medical Care) Refers to a patient's regular engagement with medical care at a health care facility after initial entry into the system (Horstmann et al, 2010).

Missed appointment This is the 'no show' to a clinic appointment on the day it is scheduled. In Kiambu County Referral Hospital, one is considered a missed appointment within one to seven days of not showing-up at the clinic or not showing any form of communication to the clinic.

Self-contained house This is a house that has at least a bathroom, toilet and kitchen facilities within the same house.

ABSTRACT

Acquired immune deficiency syndrome remains one of the most destructive epidemics the world has ever witnessed. Declaration of HIV infection as a national disaster in Kenya led to increased resource allocation and mobilization towards prevention care and treatment of HIV and AIDS. The rollout of prophylaxis and antiretroviral therapy has brought lifesaving treatment to millions of HIV-infected individuals. Advocacy and increased HIV testing and counseling coupled with availability of HIV care and treatment services has increased the uptake of HIV services in health facilities. HIV treatment is life-long and to continue the benefits, patients must remain in care. Despite this, systematic investigations of retention have documented high rates of loss to follow-up from HIV treatment programs. The main objective of this study was to determine the patient and hospital factors associated with loss to follow up among HIV positive patients in Comprehensive Care Clinic in Referral Hospital. This was a Post hoc cross sectional study conducted in Kiambu County referral hospital in 2014. HIV positive adult patients enrolled in care and documented to have been lost to follow up according to case definition were recruited. Pre-determined sampling was done to select patients who met inclusion criteria, starting with the most recent patients until the sample size of 313 was attained. Files of patients who were sampled had data abstracted and the patient were then contacted on phone and structured questionnaires administered. The resultant data was coded, cleaned, sorted and was analyzed using descriptive analysis where proportions were calculated for categorical data and summarized into tables and charts. Cross tabulations was applied to test for statistical association between variables. The Pearson's chi-square was used, where cell numbers were too small in two by two tables, the Fishers exact test and Odds ratios were applied. A p-value of less than 0.05 indicated a significant statistical association. The study found that a higher proportion of female (66.5%) than male (33.5%) was lost to follow up and most patients had Primary level of education. Ninety five percent accepted their HIV status and 95.5% had disclosed status to another significant person. The main reason for LTFU in this study was transfer out, self-transfer out, death and relocation of residence. Only 39.6% of clients who continued on treatment while LTFU from the facility reported adherence to ART; forgetting to swallow their ARVs was the main reason for non-adherence. Duration since knowledge of HIV status, treatment supporter, support group, whether or not one was on ARVs, disclosure of status and substance abuse were associated with LTFU. Strengthening service delivery systems through electronic data management, efficient patient tracking and patient centered model of care are recommended for the HIV clinic to mitigate against LTFU of patients from the facility.

CHAPTER ONE

INTRODUCTION

1.1 Background Information

HIV continues to be a major global public health issue. In 2019 an estimated 38 million people were living with HIV (including 1.8 million children), with a global HIV prevalence of 0.7% among adults (UNAIDS, 2020).

Since the start of the epidemic, an estimated 75.7 million people have become infected with HIV and 32.7 million people have died of AIDS-related illnesses. In 2019, 690,000 people died of AIDS-related illnesses. This number has reduced by around 40% since the peak of 1.7 million in 2004 and 1.4 million in 2010 (UNAIDS 2020). The HIV pandemic remains one of the most serious of infectious diseases in the public health domain (WHO, 2015; UNAIDS, 2013).

The vast majority of people living with HIV are located in low- and middle- income countries. Of the 4,500 people who contract HIV every day in the world, 59% live in sub-Saharan Africa. East and Southern Africa remains the region most affected by HIV in the world, with 20.7 million people living with HIV and 730,000 new HIV infections in 2019 (UNAIDS, 2020).

The annual incidence of HIV among adults in Kenya was 0.14% among women and 0.13% among men. This corresponds to an estimated 36, new infections per year among adults (KENPHIA, 2018). The prevalence of HIV among adults in Kenya was 4.9%, which translates to approximately 1.3 million adults living with HIV in Kenya. Among adults living with HIV who knew their HIV positive status, 96.0% were on ART, based upon self-report and the detection of ARVs in blood: 96.6% among women and 94.5% among men.

HIV prevalence among adults varied across the country, with the highest prevalence of 19.6% in Homabay County and lowest prevalence of 0.2% in Wajir, Mandela and Marsabit Counties. HIV prevalence varied across the country. According to

KENPHIA report for 2019, Kiambu County had a prevalence of 1.1%, a reduction from 3.8% in 2012 as reported by KAIS report. ((KENPHIA, 2018; KAIS, 2012)

Although there is no known cure for HIV, the virus can be suppressed by combination antiretroviral therapy (ART) consisting of three or more antiretroviral drugs. The goals of ART are maximal and durable suppression of viral replication to prevent development of HIV drug resistance and treatment failure, restoration and/or preservation of immunologic function, reduction of HIV-related morbidity and mortality (NASCOP 2011). Improvement of the patient's quality of life including prevention of unpleasant adverse drug effects of ARVs and prevention of onward transmission of HIV infection (NASCOP, 2011). To maximize effectiveness of ARVS, adequate monitoring of patients must be done to ensure long-term adherence to treatment and to diagnose complications and treatment failure as early as possible. It is recommended that everyone diagnosed with HIV take CTX, an antibiotic that reduces the risk of early mortality and rates of hospitalization, malaria, diarrhoea, and pneumonia (NASCOP, 2011). As treatment expands, other challenges emerge. Early treatment is a key challenge, and high standards of service quality must be maintained to ensure people remain on treatment, limit side effects and prevent reemergence of drug resistance (KAIS, 2012).

1.2 Etiology and transmission of the Human Immunodeficiency Virus

The Human Immunodeficiency Virus the etiologic agent for the acquired immunodeficiency syndrome belongs to the family of retroviruses (retroviridae) and genus of lentiviruses (NASCOP, 2011). HIV is an RNA virus whose protein coat (capsid) carries the chemicals that make it possible for the virus to enter the human cell (Ford *et al*, 2018). There are two subtypes of HIV, namely HIV-1 and HIV-2. Both types are transmitted via body fluids such as blood, semen and breast milk. The most common transmission route worldwide is sexual and in most cases heterosexual, the main others being vertical transmission *(in utero*, at birth or via breastfeeding), via blood transfusion or other contact with blood as in intra-venous drug use (IDU). Heterosexual transmission is the predominant mode of transmission in Sub-Saharan Africa, followed by mother-to child-transmission. HIV type 1 is the

cause of much of the global HIV pandemic and is more infective than HIV-2. Although there is evidence that different sub-types may have different genetic pathways to ART resistance (Eleano *et al.,* 2012; Mansson *et al.,* 2012) currently the sub-type diversity of HIV 1 does not appear to have implications to clinical response to recommended ARV treatment strategies (NASCOP, 2011).

1.3 Antiretroviral Therapy for HIV treatment

Highly active antiretroviral therapy (HAART) is a medication regimen used in the management and treatment of human immunodeficiency virus type 1 (HIV-1). It is composed of several drugs in the antiretroviral classes of medications. A foundation of HAART is the administration of drugs that inhibit HIV viral replication at several stages in the lifecycle through different mechanisms to prevent viral resistance to any single agent. The goals of HAART in patients with HIV infections include to reduce morbidity and mortality (AIDS and non-AIDS associated causes),improve the quality of life, reduce plasma viral RNA load, prevent transmission to others (sex partners, needle-sharing partners, mother to infant),prevent drug resistance and improve immune function (Thomson *et al*, 2012).

The timing of treatment initiation for HIV infection is important. HAART should be initiated within upon a confirmed HIV diagnosis, regardless of CD4 count or clinical symptoms. Early HAART initiation has been shown to reduce severe AIDS and AIDS-associated illnesses (Ford *et al*, 2018, Günthard *et al*, 2016). In addition, NASCOP guidelines on antiretroviral treatment (2018) recommended ARVs to all HIV-infected individuals regardless of WHO staging of the infection. Many of these medications are administered orally, once a day in a co-formulated combination tablet. Proper utilization and adherence to a HAART regimen are essential to ensure a therapeutic response and prevent viral resistance (Huesgen *et al*, 2016).

Antiretroviral therapy has reduced HIV-related morbidity and mortality at all stages of HIV infection (Severe, 2015) and has reduced HIV transmission (Cohen 2011; Reynolds, 2011). Maximal and durable suppression of plasma viremia delays or prevents the selection of drug-resistance mutations, preserves or improves CD4 T lymphocyte (CD4) cell numbers, and confers substantial clinical benefits, all of

which are important treatment goals (Mansson *et al.*, 2012). Despite these benefits, eradication of HIV infection cannot be achieved with available anti-retroviral drugs. Treatment interruption has been associated with rebound viremia, worsening of immune function, and increased morbidity and mortality, thus once initiated, ART should be continued, to achieve the key treatment goals (NASCOP, 2011).

There are five classes of anti-retroviral drugs currently in use, Nucleoside Reverse Transcriptase Inhibitors (NRTIs), Non- Nucleoside Reverse Transcriptase Inhibitors (NNRTIs), Protease Inhibitors (PIs), fusion inhibitors and integrase inhibitors. The Kenya national HIV treatment guidelines recommend the use of simplified once-a-day fixed-dose-combination ARV pill, and routine viral load determination for treatment monitoring (NASCOP, 2018).The preferred regimen consists of two nucleoside analogs combined with either a boosted PI or NNRTI or with distinct restrictions, a third nucleoside analog (NASCOP, 2018). Patients are started on first line antiretroviral regimen while those who fail are switched to second line therapy; each containing a combination of three different antiretroviral drugs.

1.4 Retention of Patients in HIV care and treatment programs

Retention in HIV care remains a major goal for HIV services worldwide. Globally default rates vary from 32.7% in America, 12.1% in Europe to 39.4 to 79.4% in Africa (Kranzer *et al*., 2010). Non-adherence to treatment reduces the immunological benefits of ARVs, which predisposes clients to opportunistic infections, increases both the risk of drug resistance and HIV transmission (Wasti *et al*., 2012)

Patient level factors that contribute to defaulting from ART include forgetfulness, fatigue and hopelessness, absence of symptoms and severity of the illness. Furthermore, lack of support from a partner, negative perceptions towards ART medication, pre-occupation and absence from home due to employment compromises adherence to ARVs. Stigma and discrimination coupled with family pressure, regular changes of residence and religious beliefs influence defaulting from ART (Shet *et al*., 2011). Financial cost associated with accessing treatment is

secondary to long distance especially among those residing in rural areas (Wasti *et al*., 2012).

Inefficient health system including inadequate counseling on benefits of ART , long waiting times , compromised privacy due to inadequate consultation rooms, intermittent supply and stock outs of antiretroviral and reagents and dissatisfaction with the care received contribute to defaulting from ART (Holtzman *et al*.,2015, Merten *et al*., 2010).

1.5 Adherence to HIV therapy

Adherence to treatment is critical to achieving these outcomes through viral suppression. Effective care of people living with HIV/AIDS (PLWHA) requires that patients are provided with satisfactory care, adhere to their treatment regimen and are retained in care (Schaecher, 2019).

Adherence to therapy is one of the primary determinants of treatment outcome. Some of the major objectives of care and treatment of HIV/AIDS are to reduce morbidity and mortality as well as improve the quality of life of the PLWHA. These objectives among other factors are intricately linked to the achievement of optimal viral suppression, which in turn depends on the level of adherence of the patient to treatment. Sustained period of good adherence (not less than 95%) to therapy is required to achieve adequate viral suppression, which is a predictor of good clinical outcome (Viswanathan *et al*, 2015).

Poor adherence on the other hand is not only associated with poorer clinical outcome but also with a risk of developing drug resistance. Poor adherence reduces the optimal clinical outcome and the overall effectiveness of the treatment goal or target. The factors directly affecting patients' level of adherence are diverse. They could be patient-related, treatment-related among others. Complexity of regimen (dosing frequency, pill burden), treatment side effects, poor health literacy, and poor patient-physician relationship have been reported to affect adherence to treatment (Schaecher, 2019).

1.6 Loss to follow up of patients from treatment programs

LTFU in this study defined as a patient who has not received ARVs in the last 90 days (three months) following their last missed appointment or missed drug pick-up (WHO, 2018). LTFU is indeed a major challenge for ART programs in resource-limited settings because it is associated with treatment disruption, subsequent ART failure, and mortality (Seifu *et al*, 2015).

Loss to follow-up of PLWH has negative impacts on their immunological status and increases their chances of suffering from opportunistic infections, which is costly to the public ART programs that are already battling limited resources. Failure on potent regimens and increased demand for subsequent regimens that are costly or not available (May *et al*, 2014). Kenya and other resource-constrained countries relies heavily on donors to finance HIV and AIDS programs.

1.7 Statement of the problem

While ART has been shown to be effective in reducing mortality among those who remain in treatment and adhere to therapy under programmatic conditions, not all patients remain in treatment. Loss to follow-up of PLWH has negative impacts on their immunological status and increases their chances of suffering from opportunistic infections, which is costly to the public ART programs that are already battling limited resources (May *et al,* 2014). LTFU in patients receiving ART can result in serious consequences, such as discontinuation of treatment, drug toxicity, treatment failure due to poor adherence, and drug resistance (Tezera *et al*., 2014). Further, LTFU patients who discontinue with care could transmit the virus through unprotected sex and through vertical transmission to their babies; this remains a public health concern. Kiambu County Referral Hospital has over 2000 patients in HIV care and treatment. Patients default scheduled appointments and even become lost to-follow up despite the health education, knowledge on importance of adherence and phone and physical follow up.

ARV treatment does not only affect the infected patient but the family and the community. New onset of significant Opportunistic Infections (OIs) or malignancy

and recurrence of previously treated OIs reduce the patient's productivity and that of the family caregivers who have to stop their normal schedules to attend to the sick and this increases the health care providers' burden as the patients are admitted to the wards. National and family resources that could have been spent elsewhere are spent on illnesses that could be prevented by proper adherence to comprehensive treatment care and support. It is essential to understand how and why people drop out of treatment programs, since retention of people on ART and ensuring adherence to treatment are critical determinants of successful long-term outcomes (Tezera *et al*., 2014). This study offered an opportunity to determine Patient and Hospital factors associated with lost to follow up as well as determining the level of treatment non-adherence among the LTFU.

1.8 Research Questions

1. What patient related factors are associated with lost to follow up of patients?
2. What hospital related factors are associated with lost to follow up of patients?
3. What is the level of non-adherence to treatment among LTFU patients?

1.9 Objectives

1.9.1 General Objective

To determine the factors associated with loss to follow up among HIV positive patients in Kiambu County Referral Hospital, Kiambu County.

1.9.2 Specific Objectives

1. To determine patient related factors associated with loss to follow up in Kiambu County Referral Hospital.
2. To determine hospital related factors associated with loss to follow up of HIV patients in Kiambu County Referral Hospital.
3. To determine the level of non-adherence among LTFU patients in Kiambu County Referral Hospital.

1.10 Justification of the study

With a better understanding of the reasons why patients are lost to follow up, interventions can be designed that improve patient's treatment retention and ultimately the patient outcomes. Non-adherence to clinical appointments is an indicator of non-compliance to treatment, whether on prophylaxis or ARVS (Tezera *et al*., 2014). Non-adherence to ARVS could result to drug resistance, which complicates the management of HIV due to the limited drugs option available. Patients who are lost, without ARVs are prone to HIV progression, and suffer low immunity and opportunistic infections. Some of them present too late to the hospital for treatment of OIs and this increases mortality.

A determination of whether patients who are Lost-to-Follow Up from the hospital are disengaged from antiretroviral treatment need to be reached. Although the area of adherence in treatment and LTFU has largely been studied, scanty studies have been documented on factors associated to LTFU from patients already lost to follow from the facility of study. There was need to identify factors associated with loss from among those lost/assumed to be lost.

The findings of this study will go a long way in bringing a better understanding of factors that influence patients to become lost to follow up at the Kiambu County Referral Hospital Comprehensive Care Centre. With this understanding, feasible strategies of addressing patient continuity of care in the facility can be developed. Stakeholders could then develop appropriate interventions to reduce missed appointment and LTFU of patients living with HIV and AIDS.

CHAPTER TWO

LITERATURE REVIEW

2.1 Adherence to care and treatment in HIV programs

Suboptimal adherence to HIV care and treatment may result in reduced treatment response (Tezera *et al*., 2014) While ART has clearly been shown to be effective in reducing mortality among those who remain in treatment and adhere to therapy (Schaecher, 2019) under programmatic conditions, not all patients remain in treatment. Non-adherence can result from complex medication regimens; patient-related factors, such as active substance abuse, depression, or the experience of adverse effects; and health system issues, including interruptions in patient access to medication and inadequate treatment education and support and conditions that promote adherence should be maximized before and after initiation of ART (DHHS, 2016). Antiretroviral Therapy is considered successful if HIV-infected persons achieve and sustain viral suppression, which is viral load of below 1000 copies of virus/dl of blood (NASCOP, 2018). In addition to known mortality while in care, some proportion of patients drop out of treatment programs and do not restart care elsewhere (David *et al*., 2020). Achievement of optimal viral suppression, which in turn depends on the level of adherence of the patient to treatment. Sustained period of good adherence (not less than 95%) to therapy is required to achieve adequate viral suppression, which is a predictor of good clinical outcome (Viswanathan *et al*, 2015).

These wide differences show that for effective strategies to be realized like for the case of Kiambu County Referral Hospital, it is important to study the factors that specifically contribute to loss to follow up from care and treatment and establish approaches and strategies to mitigate against LTFU.

2.2 Factors associated with LTFU of patients from HIV programs

Disruptions in care may undermine any individual gains in clinical outcomes. Varied factors have been documented to contribute to LTFU from ART care among patients living with HIV including individual factors such as advanced clinical and immunological disease stage, younger age, malnutrition, low education, depression, and poor psychological support (Ardura *et al*., 2015; Zuniga *et al*., 2016). The World Health Organization (WHO) reported individual risk factors for LTFU from ART care commonly reported from resource-limited countries, including feeling better, pill burden, treatment fatigue, work as well as home responsibilities, and migration—mobile populations ('silent transfers')—to other ART service providers (WHO, 2012). System/infrastructural factors contributing to LTFU from ART care have been reported from East Africa, these include longer turnaround time of laboratory tests, drug stock outs (Rachlis *et al*., 2016). In South Africa, A study on challenges with tracing people on antiretroviral therapy identified forgetting appointments, being too busy/had to work and not wanting to be seen coming to the clinic as the main factors reported among those who discontinued care (David *et al*., 2020). Another study assessing factors for loss to follow-up of HIV infected patients in Guinea-Bissau found relocation of residence, travelling and transferring to other clinics as the major reasons for LTFU (Nordentoft *et al*., 2017).In Southwest Nigeria, long distance to clinic was reported as a major reason for discontinuation of HIV care and stopping ART (Balogun *et al.,* 2019).

Evaluation of outcomes of LTFU in Western Kenya found that poor documentation led some patients to be incorrectly labeled as LTFU with a significant proportion of patients in the study originally considered LTFU later confirmed to have transferred out, missing patients may have transferred to another clinic and thus are only LTFU from the perspective of their original clinic (Rachlis *et al*., 2015). A study from Malawi found that documentation was among the main reasons that explain why patients may become LTFU (Shaweno, *et al*., 2015).

Feeling better was associated with patient's disengagement from care (Rachlis *et al.,* 2013). WHO described feeling better as a factor that contributes to LTFU (WHO, 2012). Thirty percent (30%) of interviewed patients reporting issues related to Alternative Treatment and Advice (Rachlis *et al.,* 2015).

Level of education as a factor associated with LTFU has been studied with mixed results on relationship of high or low education on care engagement. Studies have found either no association between level of education and LTFU (Decroo *et al*., 2011) or low to poor educational level being associated with LTFU (Alvarez-Uria *et al* 2013; Meloni *et al*., 2014; Tang *et al*., 2015). Determinants of loss to follow-up among HIV positive patients receiving antiretroviral therapy in a test and treat setting study found that the likelihood of LTFU was higher among patients who were less educated, such patients might find it hard to read text reminder messages plus a couple of other information education communication (IEC) materials. (Kiwanuka *et al*., 2020).

Period of time patients have been engaged in HIV care can help determine when to implement specific interventions, in lower income Countries, a study on early loss of HIV-infected patients on potent antiretroviral higher risk of attrition in the first six months of antiretroviral therapy, a period considered crucial for the long-term success of HIV treatment. (Berheto *et al*., 2014). Other studies from Ethiopia and other African countries documented findings in agreement that the probability of attrition from care was directly associated with the length of engagement with ART care where a higher proportion of LTFU was recorded within the first year after care engagement the peak period being six months (Assefa *et al.,* 2011, Berheto *et al*., 2014).

Long waiting time at the HIV clinics while waiting for review or ARVs collection was reported as a key driver in the attrition of clients on ART (Duff *et al*., 2010, Decroo *et al*., 2013). Studies also reported that negative staff attitude while attending to HIV positive clients affected retention of the clients in treatment programs (Duff *et al*., 2010; Nakigozi *et al*., 2013; Steinberg, 2008). Some authors suggest that the disconnect that sometimes exists between newly diagnosed clients

and health providers is often fueled by lack of trust (Fleming *et al*., 2017). This disconnect compromises the patient–provider communication, which is critical in retaining newly diagnosed clients (Flickinger *et al*., 2016). Patients expressed a strong preference for nice, as opposed to rude, providers, as well as strong preferences for longer versus shorter medication refill duration as expected, shorter distance, less waiting time, and longer opening hours were also desired (Zanolin *et al*., 2018). Fear of scolding and mistreatment by health care staff and family influences relationships were identified as important reasons why individuals choose to disengage from care (Rachlis *et al*., 2015).

Self-Transfer out patients may have implications on program outcomes on retention. In a Malawian study on status and reasons for treatment discontinuation among HIV infected patients on antiretroviral therapy, a sizable proportion of the LTFU patients who claimed to be "self-transferred" reported that they re-started taking their HIV medicines in other facilities. They did not disclose previous treatment history in their new facility, additionally substantial proportion of LTFU patients were untraceable because of reasons mainly related to incomplete, non-functioning or no recorded contact addresses (Tweya *et al*., 2013).

2.3 Disclosure of HIV status

Non-disclosure of HIV status and its effects in LTFU have been explored in several studies, patients who do not disclose their status are often less likely to receive social support and are unlikely to achieve optimum levels of adherence as well as remaining engaged into care and treatment (Bott *et al*., 2013). According to a study on Disclosure of HIV status and its impact on the loss in the follow-up of HIV-infected patients on potent anti-retroviral therapy programs in DRC Congo, Patients who did not share their HIV status had a higher hazard of being LTFU than those who did (Akilimali *et al*., 2017). Different levels of disclosure have been documented in different studies, a review of social and gender context of HIV disclosure in Sub-Saharan Africa gave rates of disclosure >74% while in DRC 77.1% of patients receiving ART had disclosed their HIV status (Musumari *et al*, 2014; Bott *et al* , 2013). A study found that fear of disclosing one's HIV infected

status was the most common reason for non-disclosure reported by most clients (Lusungu *et al*, 2019) A study from Uganda, Botswana and Tanzania reported that consequences of non-disclosure among patients on ART is the covert taking of medications which leads to either delayed or missed medications that lead to defaulting from care (Wasti *et al*, 2012). Early and full disclosure of one's HIV infected status has been associated with improved adherence to one's treatment (Musumari *et al*., 2014) with fear of disclosure was reported as a reason for disengagement (Rachlis *et al*., 2015).

2.4 Alcohol use and adherence to ART

Alcohol can be defined as a psychoactive drug capable of producing physiological as well as psychological dependence. Its Harmful use is associated with tremendous health, social and economic consequences. Substance use among PLHIV is a significant public health concern (Sileo *et al*., 2019) as it can advance HIV/AIDS disease progression by directly decreasing CD4, and indirectly, through its effect on poor treatment adherence (Kader *et al*., 2015). A meta-analysis of 40 studies reported alcohol drinkers were approximately 50–60% less likely to be classified as adherent, compared to those who abstained or drank relatively less (Hendershot *et al*., 2009). A systematic review and meta-analysis study on prevalence of Alcohol Use Disorders among people living with HIV showed that the average worldwide prevalence of AUD among patients with HIV/AIDS was found to be 29.8% (Duko *et al*. 2019). Other earlier studies in Africa reported that the prevalence of AUD ranges from 17 to 39.4% in Nigeria, 1.4 to 33% in Uganda, 6.6 to 48.5% in South Africa 5.4 to 33% in Kenya, and 14.8% in Zambia WHO, 2014). Of the few studies to examine multiple levels of alcohol use, some have found a positive and linear relationship between drinking and medication non-adherence, whereas others have found similar adherence rates across moderate and high drinking levels (Azar *et al*., 2010). Evidence also suggests a deleterious influence of alcohol use on markers of immunological functioning and viral suppression (Sileo *et al*., 2019).

2.5 Role of support groups in treatment engagement

Support groups have been documented to enhance linkages to and retention of newly diagnosed clients in care (Siyabonga *et al.,* 2019). A study conducted in rural Zimbabwe showed that the role of community HIV groups appears to be that of improving access to care and increasing client's participation in health care (Campbell *et al.,* 2013). The authors of one study (Kemp *et al.,* 2016) found that linking and retaining newly diagnosed clients in the health system requires strategies such as support groups. Other scholars contend that retaining clients in care through psychosocial support strategies such as support groups yield better health outcomes and mitigate the effects of HIV/AIDS stigma (Bateganya *et al.,* 2015). Newly diagnosed clients benefit from the support groups' ability to mitigate the effects of stigma (Bateganya *et al.,* 2015; Siyabonga *et al.,* 2019). Some studies suggest that the mitigation of stigma through support group participation increase the engagement of PLHIV in care and facilitate HIV disclosure as well as HIV acceptance (Catona *et al.,* 2015). Literature suggests that PLHIV find it hard to accept an HIV-positive diagnosis, with some struggling to comply with their clinic schedules due to lack of support (McLean *et al.,* 2017; Stricker *et al*., 2014). Support groups play a critical role in supporting newly diagnosed clients to acceptance of HIV positive status (Qiao *et al.,* 2015; Syabonga *et al*, 2019).

2.6. Conceptual Framework

Independent Variables **Dependent Variables**

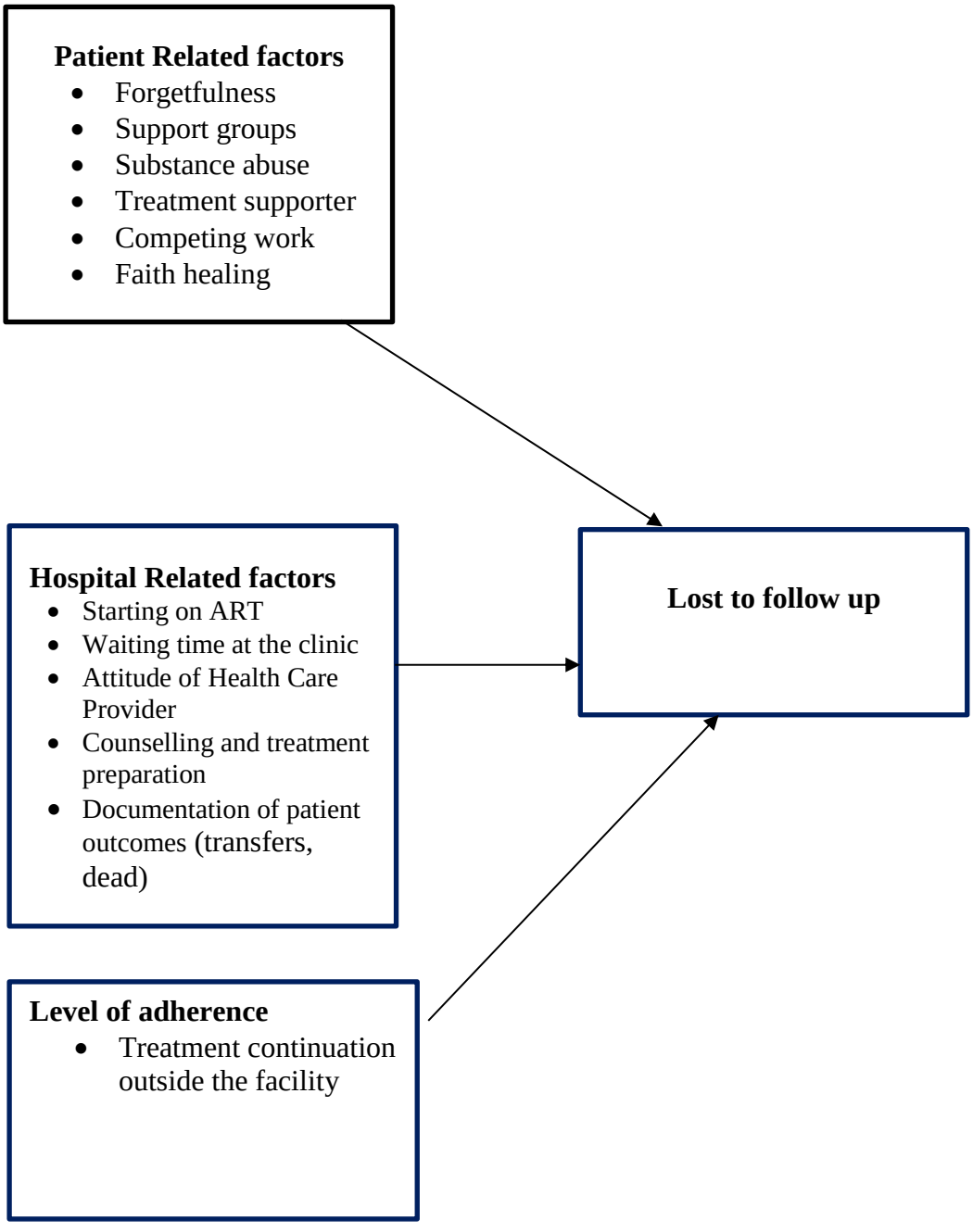

Figure 2.1: Conceptual framework

CHAPTER THREE

METHODOLOGY

3.1 Study Site

The study was carried out at Kiambu County Referral hospital in Kiambu County Referral Hospital, a public health institution under the Ministry of Health located in Kiambaa sub-county within Kiambu County. The hospital largely serves as a referral hospital for five sub counties; Kabete, Kikuyu, Githunguri, Lari and Kiambaa although, due to the excellent road network the Hospital also serves patients from the neighboring Counties mainly Nairobi and Kajiado. The hospital serves a large number of HIV and AIDS clients attended at the Comprehensive Care Clinic (CCC) commonly referred to as HIV clinic. The clinic is elaborate with various service delivery rooms including; three consultation rooms, a counselling room, HIV counselling and testing room, a dispensing pharmacy and a patient waiting area. The Laboratory is integrated within the hospital laboratory. Staff working at the clinic consisted of medical officers, clinical officers, nurses and pharmaceutical staff working in the hospital. HIV treatment, counselling, laboratory tests and follow up are offered to all patients at no cost.

3.2 Study Design

This was a hospital based Post hoc cross sectional study conducted between June and December 2014, among the Lost to follow up patients in Kiambu County Referral Hospital

3.3 Study Population

The study population consisted of adult patients living with HIV who were lost to follow up at the Kiambu County Referral Hospital Comprehensive Care Clinic. By June 2014, total active patients in the clinic were 3027 and patients ever enrolled were 6800. Total Lost to follow up patients were 2875, 732 had transferred out to

other facilities and 166 had died. The study participants were sampled from those who were lost to follow up.

3.4 Sampling Techniques

Pre-determined sampling was done by Selection of eligible sample starting with the most recent LTFU patients until the sample size was attained. This method was suitable because of the hospital filing system that retains inactive files for 10 years and the fact that HIV care and treatment has had major changes that would significantly affect the data if the sampling were done randomly for cumulative patients LTFU patients.

3.4.1 Inclusion Criteria

The following LTFU patients from Kiambu County Referral Hospital were included in the study.

- HIV positive patients aged 15 years and above enrolled in care in the HIV clinic and who were lost to follow up
- Patients who consented

3.4.2 Exclusion Criteria

The following LTFU patients from Kiambu County Referral Hospital were excluded from the study.

- HIV positive patients who were below 15 years of age
- HIV positive patients who missed their scheduled appointment but returned to clinic within 90 days.
- Patients who did not consent

3.5 Sample size determination

The sample size was calculated using the formula by Daniel (1999) for descriptive studies with 95% level of confidence and degree of precision at ±5%. Retention rate for the hospital was at 60%.

$$n = \frac{NZ^2\,PQ}{d^2(N-1) + Z^2\,PQ}$$

Where n represents minimum required sample size

N = estimated population of HIV patients lost to follow up at the participating clinic

Z = standard normal deviate for 95% confidence level = 1.96

P = estimate proportion of HIV patients lost to follow up = 40% (then P= 0.4)

Q = 1-P (then Q = 1-0.4 = 0.6)

d = desired precision around estimated retention rate (set at ± 5%, then d = 0.05)

The total cumulative number of patients as at June 2014 that were lost to follow up in the CCC clinic was 2875 (Kiambu CCC internal data). The population of patients under the age of 15 was 5.23% whereas the total patients aged 15 years and older were 2865. The calculated minimum sample size was therefore 313.

3.6 Data collection tools

Structured questionnaires (Appendix 1) were developed for data collection. The questionnaire captured the social demographic characteristics, patient and hospital factors affecting adherence to clinic and treatment of the patients at the Comprehensive Care Clinic. The tool was piloted on 20 patients to make sure questions were not ambiguous and to eliminate questions that did not yield usable data. The research assistants who assisted to collect the data were trained before data collection.

3.7 Data collection Techniques

The primary technique was data abstraction from the files and the use of cell phone to reach the sampled patients. Patients were called on their phone numbers and requested to come to the clinic on a day that was agreed upon, the researcher and the trained assistants filled in the questionnaires as the patients responded. Home visits were done for patients not reachable on phone and whose residence were within the hospitals catchment area; a community worker from the CCC accompanied the interviewers for physical home visits. Some of the challenges of home visits were unclear landmarks for patients residence, relocation of patients especially those in rented houses, patient not around at the time of visit and not consenting to participate. As a routine patients contacts are recorded in the patients clinical notes and all patients on enrollment are informed and given an explanation on why, when and who can call them on the hospital phone.

3.8 Data Analysis

The completed questionnaires were checked daily to ensure completeness. The questionnaires were numbered and coded for ease of handling. Coding and indexing was done and involved assigning numeric variables to each response. Prior to data entry into an excel spread sheet, data were examined and checked by the principal investigator for completeness and accuracy. It was then exported SPSS version 20 for analysis.

Data was analyzed using descriptive analysis where proportions were calculated for categorical data and summarized into tables and charts. Cross tabulations was applied to test for statistical association between variables. The Pearson's chi-square was used and where cell numbers were too small in two by two tables, the Fishers exact test and Odds ratios were applied. A p-value less than 0.05 indicated a significant statistical association.

3.9 Ethical Considerations

The study was presented for ethical approved by the Kenyatta National Hospital and University of Nairobi Ethics and Research committee (Appendix 5) and permission to conduct the study was given by the Medical Superintendent Kiambu County and Referral Hospital. In a private room, the interviewer explained the study particulars, details of the consent document in either English or Kiswahili according to participants language of choice (appendix1 and 2) including the fact that participation was voluntary. The participants were further informed that the decision not to take part in the study would not affect their future treatment and care in the hospital. Participants were additionally informed that there were no direct benefits to them but that the study results would help the hospital in decision making regarding HIV care and treatment. Participants were assured of confidentiality and anonymity during data collection, storage, analysis and in any write-up. Informed consent was obtained from patients by requesting them to sign an informed consent form (Appendix 3 and 4).

CHAPTER FOUR

RESULTS

4.1 Introduction

A total of 313 lost to follow up patients from Kiambu County and Referral Hospital in the month of June 2014 were sampled with a view to determine factors associated with loss to follow up among HIV positive patients in comprehensive care clinic at the Kiambu County Referral Hospital. The results are presented in three parts; socio demographic characteristics, patient and hospital related factors associated with the loss to follow up. Figure 4.1 below shows general outcome summary of the LTFU patients.

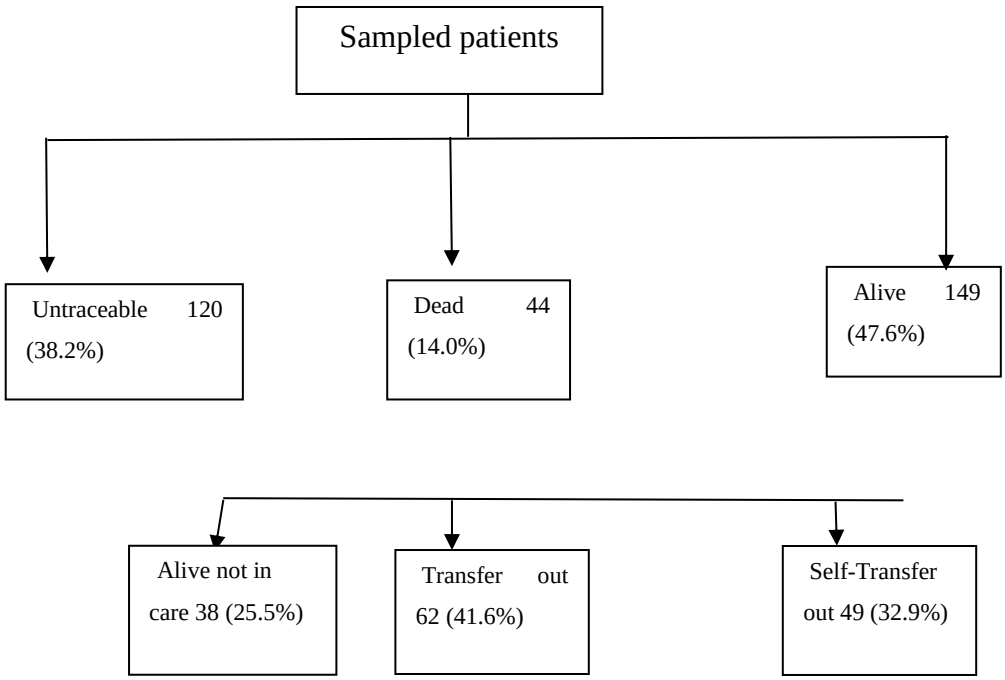

Figure 4.1: General outcome of Lost-to-follow-up

4.2 Socio-demographic characteristics of patients

Table 4.1 shows that the study patients were aged between 16 and 72 years with a mean age 36.8 years (SD 9.07), majority (44.1%) being in the age group 36 to 50

years. There were 33.5% males and 66.5% females giving a male-to-female ratio of 1:2. A high number (66%) of the study patients were married, majority (67.1%) married to one partner. The study population had a mean household size of 2.1 (SD1.61). Most patients (50.8%) had primary level education.

Majority (34.1%) of the study patients were self-employed, 29.2% formally employed, 19.7% relied on casual jobs and 17% had no employment. More than half (55%) of the patients lived in rented houses, while 21.2% lived in their own homes, with a big majority (56.8%) living in permanent houses. Many patients 38.4% were living in two roomed houses and only 9% lived in self-contained houses. Twenty seven percent and 25% of the patients had two and three persons financially depending on them respectively.

Table 4.1: Descriptive analysis

Social demographic characteristic	Frequency	Percentage
Sex (n=313)		
• Male	105	33.5
• Female	208	66
What is your highest completed level of education? (n=258)		
• None	11	4.3
• Primary	131	50.8
• Secondary	95	36.8
• Tertiary	21	8.1
Are you married? (n-306)		
• Yes	199	66
• No	107	35
If yes above, what is your marital status? (n=207)		
• Married to one partner	139	67.1
• Married to more than one partner	6	2.9
• Divorced/separated	45	21.7
• Widowed	17	8.2
What is your present occupation? (n=264)		
• Employed	77	29.2
• Self-employed	90	34.1
• Unemployed	45	17.0
• Casual labourer	52	19.7
What is the ownership of the house you live in?		
• Rented	83	55
• Own house	32	21.2
• Others	36	23.8
In what type of a house do you live in? (n=146)		
• Permanent	83	56.8
• Semi-permanent	58	39.7
• Temporary	5	3.5
What is the size of the house you live in? (n=146)		
• One room	23	15.8
• Two room	56	38.4
• More than 2 rooms	53	36.3
• Self-contained	14	9.6
How many people depend on you financially? (n=208)		
• 1	51	24.5
• 2	56	26.9
• 3	52	25
• 4	49	23.6

4.3 Patient related Loss to follow up factors

4.3.1 Diagnosis and disclosure of HIV status

Based on self-reporting, table 4.2 shows that 94.8% patients had accepted their HIV status and 95.5% had disclosed their HIV status to someone. Majority, (47%) had disclosed to their partners, 20.3% had disclosed the status their sibling, to their parents and 11.1% had disclosed to their son or Daughter. Only 7.5% had their HIV disclosed to a friend, church clergy or work supervisors.

Table 4.2: Patient related lost to follow up factors

Factor	Frequency	Percentage
Have you accepted your HIV status? (n=307)		
• Yes	291	94.8
• No	16	5.2
Have you disclosed your HIV status to anyone (n=309)		
• Yes	295	95.5
• No	14	4.5
If yes above, please indicate to whom you have disclosed? (n=296)		
• Partner	139	47
• Friend	12	4.1
• Sibling	60	20.3
• Parent	42	14.2
• Son/daughter	33	11.1
• Other(work supervisor, church clergy)	10	3.4

4.3.2 Treatment supporters follow up on patients' adherence to appointments

As illustrated in Figure 4.2, 92.2% of patients had treatment supporters whose contacts were documented at the clinic while 7.8% did not have their supporters documented on the patients' charts. Of those with treatment supporters, 81.3% were inquisitive on the patient's adherence to medication and scheduled appointments. Another 83.9% of the treatment supporters were aware that the patient missed appointments or was lost to follow up at the clinic.

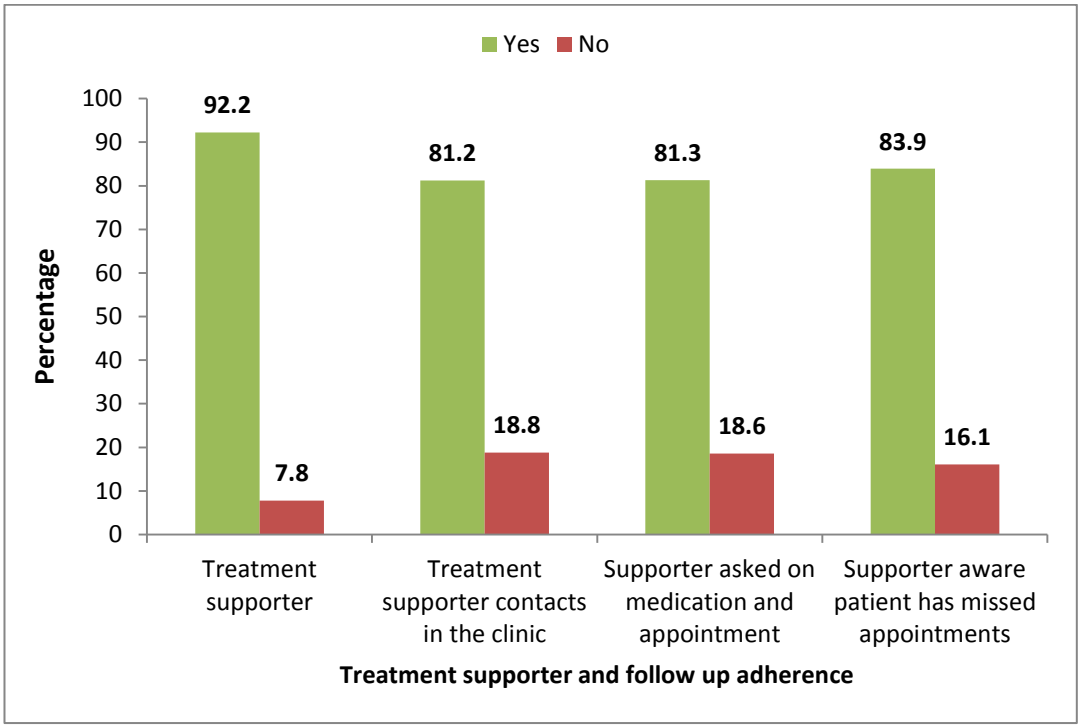

Figure 4.2: Treatment supporter and follow up adherence

4.3.3 Duration of knowing HIV status among LTFU patients

igure 4.3 below shows that 69.6% of the study patients reported having learnt of their HIV status more than two years prior to this study while 4.2% indicated they had learnt of their HIV status within a year of the study.

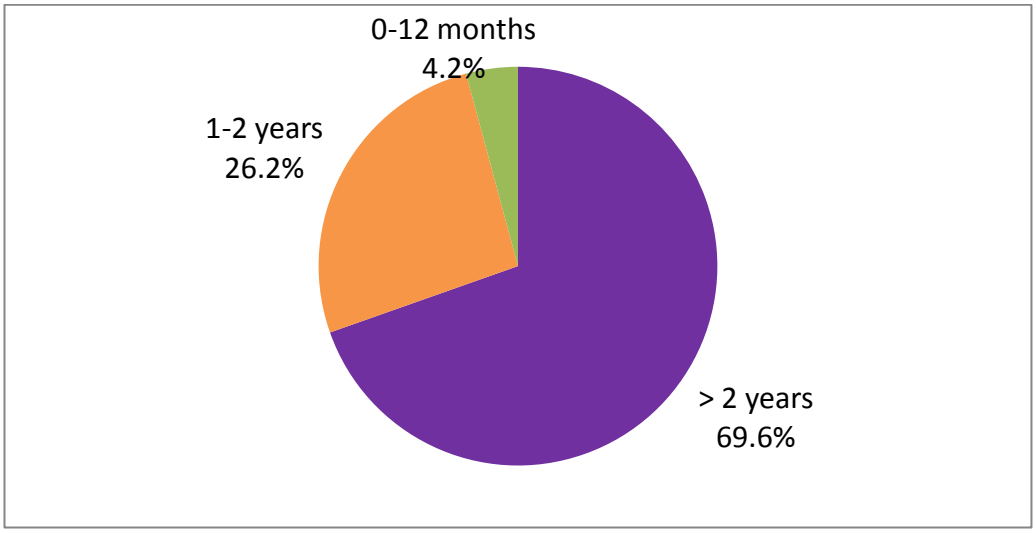

Figure 4.3: Duration of knowing HIV status among LTFU patients

4.3.4 Substance abuse and HIV support groups

A significant number of study patients (82.5%) did not report any substance or alcohol abuse, while a minority 16.7% had joined and were active in an HIV support group, Figure 4.5.

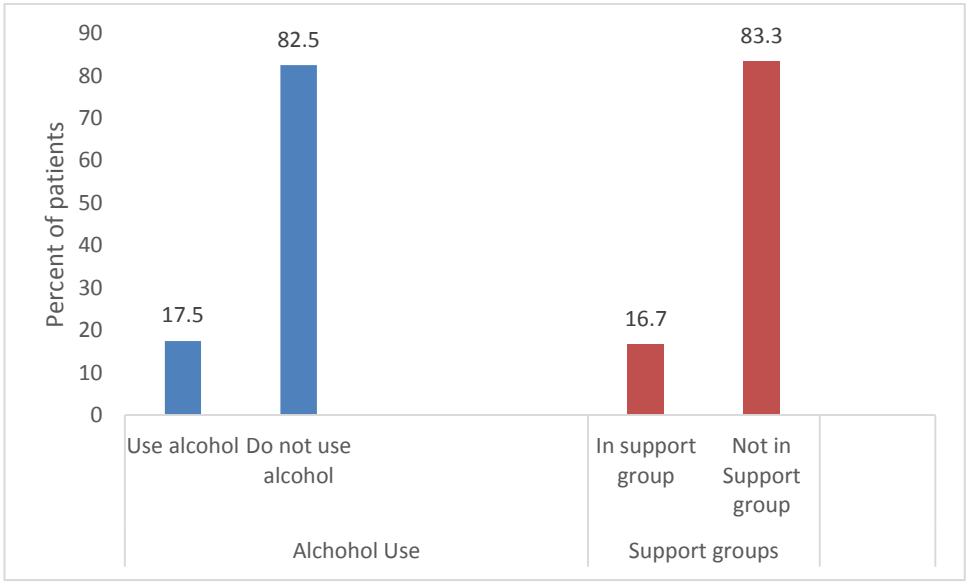

Figure 4.4: Substance abuse and support groups involvement among LTFU patients

4.4 Hospital Related Factors associated with loss to follow up

4.4.1 Reasons why clients stopped attending clinic in the facility

Figure 4.5 illustrates the main reason given for lost to follow up was transfer out of the facility in 19.8% of study patient, 15.7% self- transferred, 13% of clients had already died by the time of this study, while 11.2% had relocated to other places of residence. Other reasons included health provider attitude, feeling better, distance and lack of fare to the facility, alcoholism, personal problems and delays at the clinic.

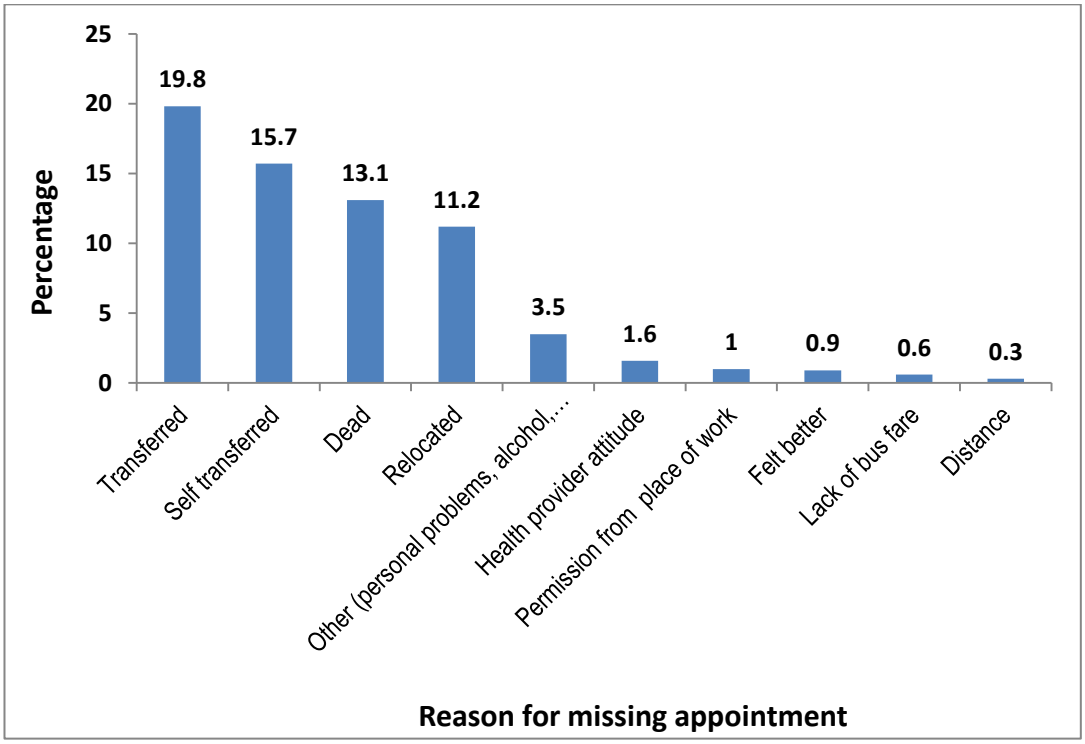

Figure 4.5: Reason for missing clinic appointment

4.4.2 Initiation and duration of ARV and Septrin treatment among LTFU patients

As indicated in Table 4.3, a significant number 95.8% of study patient had counseling on adherence to medication. Of the 309 who indicated they were on ARVS, 75.7% started on ARVs by the time of this study. 89.1% indicated to have started their HIV clinics at the Kiambu County Referral Hospital. Almost all the study patients 99.4% had started septrin/Cotrimoxazole or Dabsone medication.

Table 4.3: Hospital related factors

Factors	Frequency	Percentage
When you enrolled into this clinic, were you counseled about how to take your Septrin and or ARVs?		
• Yes	271	95.8
• No	12	4.2
Have you ever been started on ARVs? (n=309)		
• Yes	234	75.7
• No	75	24.3
Did you start your HIV clinics in this facility?		
• Yes	278	89.1
• No	34	10.9
Have you ever been started on Septrin/ Cotrimoxazole or Dabsone?		
• Yes	310	99.4
• No	2	6
For how long have you not attended a clinic visit in this facility?		
• 4-6 months	19	6.2
• 6-12 months	125	40.6
• > 12 months	164	53.2

4.4.3 Patients perception to treatment at the facility

Figure 4.6 illustrates that 39.3% of the study patients were counseled on clinic attendance and adherence to treatment. 29.9% complained of waiting time, 21.3% of patients felt welcome at the facility while 9.0% indicated that they were quarreled by the health staff when they returned after missing an appointment(s).

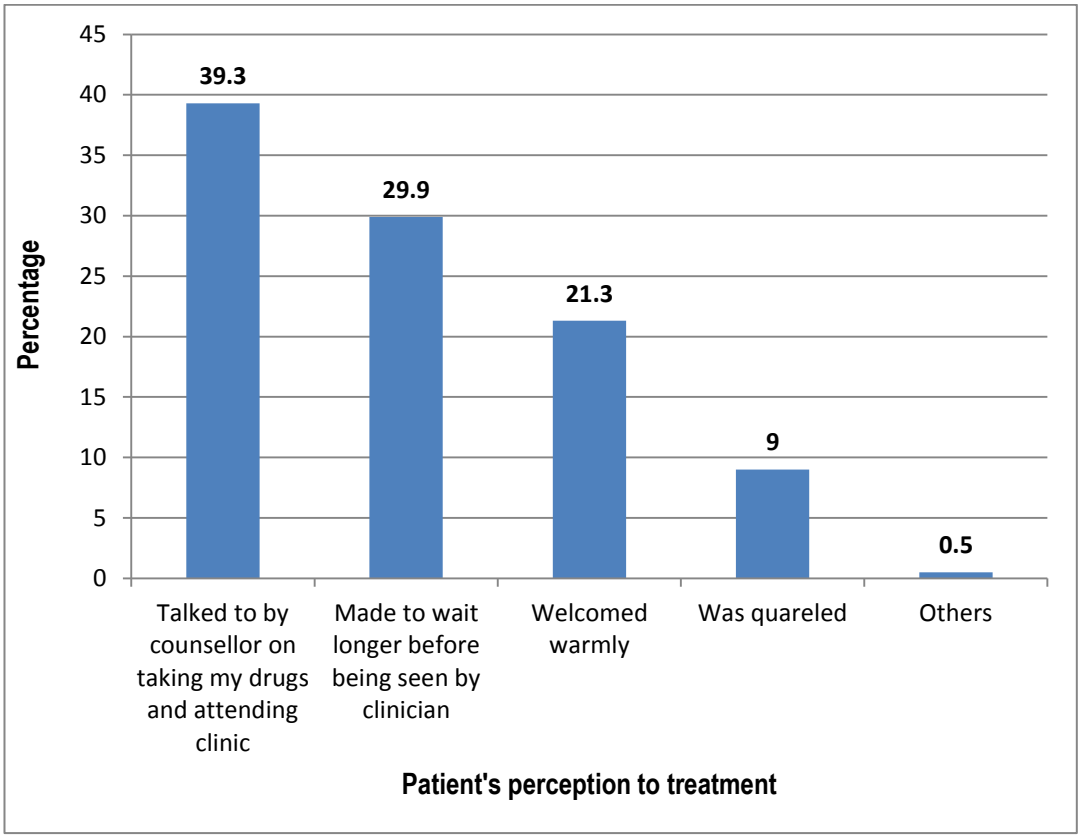

Figure 4.6: Patients perception to treatment

In table 4.4 below, 74.2% of the study patients would opt out of the Kiambu referral county hospital given the option, the main reason given by 61.3% of the patients being long queues while being made to wait if one had missed an appointment given by 31.3%.

Table 4.4: Client choice of clinic for ART medication and reasons for their options.

Factors	Frequency	Percentage
If given a chance, would you opt to leave this clinic for another?		
• Yes	115	74.2
• No	40	25.8
If yes above, please give reasons why you would opt for another clinic		61.3
• Long queues	192	61.3
• Clinic starts late		
• Staff unfriendly, quarrelsome, bad attitude, not understanding	3	1
• Made to wait if one had missed an appointment	98	31.3
• Distance	5	1.6
One patient could give as many responses as were applicable		

4.4.4 Follow up of clients after missed appointment

Fifty-eight percent (58%) of clients received a phone call from the health facility to find out why they had missed an appointment. Majority of clients 89.6% reported that they comfortably discussed their next appointment with the clinician.

Table 4.5: Client follow up after missing appointment

Factors (Appointment)	Frequency	Percentage
Follow up		
Did you get a phone call from the clinic the day you did not attend your clinic visit?		
• Yes	102	57.6
• No	75	42.4
Do you find it easy to discuss your next appointment date with your clinician?		
• Yes	120	89.6
• No	14	10.4

4.5 Adherence to ARV among the LTFU

4.5.1 Continuation with ARV treatment after being LTFU from Kiambu County Referral Hospital

On drug adherence, 25% of the patients collected drugs from another facility while 37% had extra drugs and therefore had continued with their treatment even after missing their scheduled appointment while 38% did not take any medication, Figure 4.7.

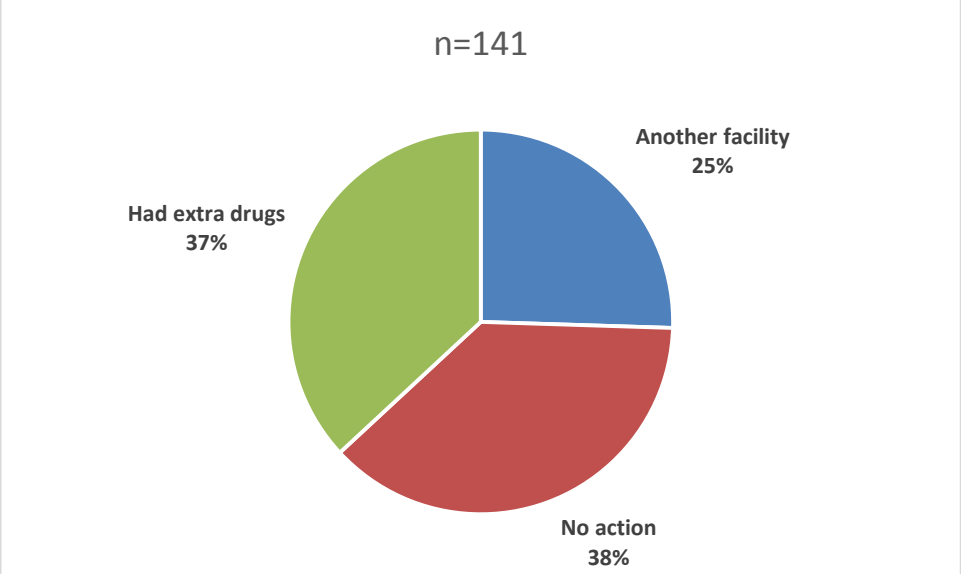

Figure 4.7: Action after missed appointment

4.5.2 Non-adherence to treatment among the LTFU

Many study patients had skipped their medication, 60.4% and 68.1% reported to have forgotten to swallow ARVs and Septrin respectively. Forgetting to take the medicines was the most common reason for non-adherence to medication indicated by 39.5% of the patients, 16.8%, 16% and 10.9% indicated the reasons to drugs being out of supply the drugs supply, travelling and feeling sick respectively. Self-reported adherence among the patients LTFU in Kiambu County Referral hospital was therefore 39.6%. Table 4.6.

Table 4.6: Non-adherence to treatment among the LTFU

Factors	Frequency	Percentage
Are there times you have not swallowed your ARVs? (n=169)		
• Yes	102	60.4
• No	67	39.6
Are there times you have not swallowed your Septrin?		
• Yes	115	68.1
• No	54	31.9
If yes above, what was the reason for not swallowing medicines?		
• Felt sick	13	10.9
• Forgot to take	47	39.5
• Had travelled	19	16
• Felt better	5	4.2
• Feared others would know my status	9	7.6
• Was out of supply	20	16.8
• Others	6	5

4.5.3 Continuation of treatment among the LTFU patients

Among patients LTFU from Kiambu County Referral Hospital, 77.6% and 77.2% were still currently taking ARVs while 77.2% continued with Septrin/Cotrimoxazole or Dabsone by the time of study.

Table 4.7: Continuation of treatment among the LTFU patients

Factors	Frequency	Percentage
Have you ever been started on ARVs? (n=309)		
• Yes	234	75.7
• No	75	24.3
Are you currently taking ARVS?		
• Yes	104	77.6
• No	30	22.4
Are you currently taking Septrin/Cotrimoxazole or Dabsone?		
• Yes	125	77.2
• No	37	22.8

4.6 Bivariate Analysis

4.6.1 Patient factors by duration of learning HIV status

As indicated in Table 4.8, the most common reason for failing to take medication among patients who learnt about their status one to two years ago and more than 2 year ago was not picking drugs, indicated by 46.2% and 18.8% respectively.

Duration since knowledge of HIV status was associated with adherence (p=0.001) though numbers were small. For patients who learnt about their status more than 1 year ago there were various reasons for stopping medication compared to those who had learnt of their status less than 1 year prior to the study.

There was a significant statistical association (p=0.001) between duration since learning of HIV status and duration of not attending clinic, with duration of not attending clinic growing for patients who had known their status longer than 2 years.

Table 4.8: Patient factors by duration of learning of HIV status

Patient Factor	When did you learn your HIV status? 0-12 months ago	1-2 years ago	More than 2 years ago	P value
What made you stop?				
• Felt sick	1 (100%)	1 (6.3%)	0 (0%)	
• Travelled	0(0%)	1 (6.3%)	1 (3.8%)	0.001
• Did not pick drugs	0(0%)	3 (18.8%)	12 (46.2%)	
• Doctor stopped me	0(0%)	1 (6.3%)	3 (11.5%)	
• Others	0 (0%)	10 (62.5%)	10 (38.5%)	
How long had you not attended clinic?				
• 4-6 months	4 (30.8%)	4 (4.9%)	11 (5.1%)	0.001
• 6-12 months	9 (69.2%)	39 (48.1%)	77 (36.0%)	
• > 12 months	0(0%)	38 (46.9%)	126 (58.9%)	
How were you treated when you visited after missing appointment?				
• Welcomed warmly	4 (57.1%)	7 (20.6%)	34 (34.7%)	0.142
• Made to wait longer	2 (28.6%)	19 (55.9%)	38 (38.8%)	
• Quarreled	0 (0%)	3 (8.8%)	3 (3.1%)	
• Counselled	1 (14.3%)	4 (11.8%)	23 (23.5%)	
• Other	0 (0%)	1 (2.9%)	0 (0%)	
When you missed appointment where did you collect your drugs from				
• Another facility	1 (16.7%)	9 (22.5%)	26 (27.4%)	
• Stayed without	2 (33.3%)	15 (37.5%)	36 (37.9%)	0.911
• Had extra drugs to take	3 (50.0%)	16 (40.0%)	33 (34.7%)	
Are there times patient did not take ARVs?				
• Yes	5 (62.5%)	25 (58.1%)	72 (61.0%)	0.939
• No	3 (37.5%)	18 (41.9%)	46 (39.0%)	
Are there times patient did not take Septrin?				
• Yes	5 (62.5%)	31 (66.0%)	88 (69.3%)	0.862
• No	3 (37.5%)	16 (34.0%)	39 (30.7%)	
Reasons for not taking medicine				
• Felt sick	2 (50.0%)	4 (12.5%)	7 (8.4%)	0.511
• Forgot	1 (25.0%)	11 (34.4%)	35 (42.2%)	
• Travelled	1 (25.0%)	3 (9.4%)	15 (18.1%)	
• Felt better	0 (0%)	2 (6.3%)	3 (3.6%)	
• Feared others would know my status	0 (0%)	4 (12.5%)	5 (6.0%)	
• Was out of supply	0 (0%)	6 (18.8%)	14 (16.9%)	
• Others	0 (0%)	2 (6.3%)	4 (4.8%)	

4.6.2 Disclosure of HIV status by duration not attended clinic

Most study patients (48.8%) who had not attended clinic for lesser than 1 year, had disclosed their HIV status. A big number of patients (85.7%) who had not attended clinic for longer than 1 year had not disclosed their HIV status to anyone. There was

a statistical significant association between duration of not attending clinic and patient disclosure of HIV status to anyone as shown in Table 4.9.

Table 4.9: Disclosure by duration of clinic attendance

	Disclosure of HIV status to anyone	
Patient factor	**Yes**	**No**
Duration not attended clinic (months)		
• 4-6	18 (6.2%)	1 (7.1%)
• 6-12	124 (42.6%)	1 (7.1%)
• > 12	149 (51.2%)	12 (85.7%)
Total	**291 (100%)**	**13 (100%)**

p=0.028

* Cell numbers less than 5.

4.6.3 Disclosure of HIV status by giving treatment supporters contacts to the clinic

According to Table 4.10 Majority of study patients who had disclosed their HIV status to someone (80.4%) had given their treatment support contacts to the clinic. There was a significant statistical significance between disclosure of HIV status and giving treatment supporters contact to the clinic (P=0.000, OR 9.250; CI (2.745-31.168). The patients who disclosed their HIV status had higher odds of giving their treatment supporter's contacts to the clinic.

Table 4.10: Disclosure of HIV status by giving treatment supporters contacts to the clinic?

Have you disclosed your HIV status to anyone	**Given treatment supporters contacts to the clinic?**		
	Yes	**No**	**Total**
Yes	222 (80.4%)	54 (19.6%)	276 (100.0%)
No	4 (30.8%)	9 (69.2%)	13 (100.0%)
Total	**226 (78.2%)**	**63 (21.8%)**	**289 (100.0%)**

p=0.000; OR 9.250; CI (2.745-31.168)

4.6.4 Disclosure of HIV status by support from treatment supporters

Table 4.11 shows that among the patients who had disclosed their HIV status to someone, (85.4%) got support from their treatment supporter while majority of those who had not disclosed their HIV status (88.9%) did not. A statistically significant association between disclosure of HIV status and getting support from treatment supporters was achieved (P=0.000, OR 46.769; CI (5.613-389.665).

Table 4.11: Disclosure of HIV status by support from treatment supporters

Have you disclosed your HIV status to anyone	If treatment supporter asked to know how well patient is taking your medication or attending your clinic visits?		
	Yes	**No**	**Total**
Yes	152 (85.4%)	26 (14.6%)	178 (100.0%)
No	1 (11.1%)	8 (88.9%)	9 (100.0%)
Total	153 (81.8%)	34 (18.2%)	187 (100.0%)

p=0.000; OR 46.769; CI (5.613-389.665)

***** one cell numbers less than 5

4.6.5 Disclosure of HIV status by treatment supporter's awareness of missed/stopped

Disclosure of HIV status had a significant association to treatment supporter awareness of missed or stopped clinic appointments (P=0.000; OR 24.500 CI (4.782-125.512). Treatment supporters were more aware of patients missed or stopped appointment for patients who had disclosed their HIV status to someone (87.5%) than those who had not as shown in Table 4.12.

Disclosure of HIV status was not statistically significant with:

- Are there time you have not swallowed your ARVs

Table 4.12: Disclosure of HIV status by treatment supporter's awareness of missed/stopped clinic appointment

Have you disclosed your HIV status to anyone	If treatment supporter is aware you have missed /stopped clinic appointments?		Total
	Yes	No	
Yes	154 (87.5%)	22 (12.5%)	176 (100.0%)
No	2 (22.2%)	7 (77.8%)	9 (100.0%)
Total	**156 (84.3%)**	**29 (15.7%)**	**185 (100.0%)**

p=0.000; OR 24.500; CI (4.782-125.512)

***** one cell numbers less than 5

4.6.6 Hospital factors by duration of learning HIV status

Table 4.13 shows that all the study patients who had learnt of their HIV status less than a year prior to the study had a treatment supporter, proportions declined with the duration since learning of HIV status. This was also the case for patients giving their treatment support contacts to the clinic where proportion declined as the duration since knowledge of HIV status rose, (p=0.051) and (p=0.047) respectively.

Table 4.13: Hospital factors by duration of learning HIV status

Hospital Factor	When did you learn your HIV status?			P value
	0-12 months ago	1-2 years ago	More than 2 years ago	
Do you have a treatment supporter?				
• Yes	12 (100%)	78 (97.5%)	182 (89.7%)	0.051
• No	0(0%)	2 (2.5%)	21 (10.3%)	
Given treatment supporter contacts to the clinic?				
• Yes	12 (100%)	67 (83.8%)	149 (79.4%)	0.047
• No	0(0%)	13 (16.3%)	50 (25.1%)	
Given a chance would you opt to leave Kiambu county hospital clinic?				
• Yes	6 (85.7%)	31 (77.5%)	78 (72.2%)	0.627
• No	1(14.3%)	9 (22.5%)	30 (27.8%)	
Have you enrolled in another facility?				
• Yes	6 (75.0%)	33 (76.7%)	102 (79.7%)	0.888
• No	2(25.0%)	10 (23.3%)	26 (20.3%)	
Easy to discuss next appointment with clinician?				
• Yes	7 (100%)	25 (83.3%)	88 (90.7%)	0.333
• No	0 (0%)	5 (16.7%)	9 (9.3%)	

4.6.7 Patients started on ARVs by enrolling in another facility after stopping appointments

In this study according to Table 4.14, a high number of patients who had been started on ARVs had enrolled in another facility (81.9%), compared to those who had not been started on ARVS as shown in table 4.13. The odds of patients on ARVs enrolling in another facility were high (p=0.030; OR 2.723; CI (1.185-6.258).

Table 4.14: Patients started on ARVs by enrolling in another facility after stopping appointments

Have you ever been started on ARVs?	Since patient stopped attending appointment have they enrolled in another facility		Total
	Yes	No	
Yes	118 (81.9%)	26 (18.1%)	144 (100.0%)
No	20 (62.5%)	12 (37.5%)	32 (100.0%)
Total	138 (78.4%)	38 (21.6%)	176 (100.0%)

p=0.030; OR 2.723; CI (1.185-6.258)

4.6.8 Patients started on ARVs by finding it easy to discuss next appointment date

Table 4.15 shows that patients on ARVs found it easier to discuss their next appointment with their clinicians (93.3%). Among patients not on ARVs, 23.1% did not find it easy to discuss their next appointment with their clinicians compared to only 6.7% among patients on ARVs (p=0.022; OR 4.200 CI (1.275-13.830).

Table 4.15: Patients started on ARVs by finding it easy to discuss next appointment date

Have you ever been started on ARVs?	Do you find it easy to discuss you next appointment date with your clinician?		
	Yes	No	**Total**
Yes	98 (93.3%)	7 (6.7%)	105 (100.0%)
No	20 (76.9%)	6 (23.1%)	26 (100.0%)
Total	118 (90.1%)	13 (9.9%)	131 (100.0%)

p=0.022; OR 4.200 CI (1.275-13.830)

4.6.9 Currently taking ARVS by where Patient picked their drugs when they skipped an appointment

Table 4.16 shows that most patients on ARVs had extra drugs to take while most of the patients not taking ARVs did without the drugs. There was greater action from patients on ARVs when they skipped their appointment to collect their drugs (P=0.000).

Table 4.16: Currently taking ARVS by where Patient picked their drugs when they skipped an appointment.

Patient currently taking ARVS	When patient skipped an appointment, where did they collect their drugs from			
	Another facility	**Just stay without**	**Had extra drugs to take**	**Total**
Yes	26 (35.1%)	13 (17.6%)	35 (47.3%)	74 (100.0%)
No	4 (16.7%)	17 (70.8%)	3 (12.5%)	24 (100.0%)
Total	30 (30.6%)	30 (30.6%)	38 (38.8%)	98 (100.0%)

p=0.000

4.6.10 Currently taking ARVS by treatment of patient after missing an appointment

After missing an appointment, more patients (44.3%) on ARVS were made to wait longer compared to those who were not on ARVs, a higher number of patients on ARVs, 22.8% were counseled on taking drugs and clinic attendance compared to those who were not on ARVs. More patients not on ARVs (47.6%) were given a warm welcome. Current intake of ARVs was statistically significantly associated to health care attitude (P=0.024) as shown in Table 4.17

Table 4.17: Currently taking ARVS by treatment of patient after missing an appointment

	The next time you visited the clinic after missing an appointment, how were you treated in the clinic? Tick all that are appropriate					
Patient currently taking ARVS	**Welcomed warmly**	**Made to wait longer before been seen by clinician**	**Was quarreled**	**Was talked to by a counsellor on taking my drugs and attending clinic on time**	**Others**	**Total**
Yes	24 (30.4%)	35 (44.3%)	1 (1.3%)	18 (22.8%)	1 (1.3%)	79 (100.0%)
No	10 (47.6%)	6 (28.6%)	3 (14.3%)	2 (9.5%)	0 (0.0%)	21 (100.0%)
Total	34 (34.0%)	41 (41.0%)	4 (4.0%)	20 (20.0%)	1 (1.0%)	100 (100.0%)

p=0.024

4.6.11 Currently taking ARVS by If given a chance, would the patient opt to leave the clinic for another clinic

As indicated in Table 4.18, given a chance to leave the clinic, a high proportion of the study patients on ARVs (82.3%) would opt to do so compared to the ones not on ARVS. Statistical association between ARVs intake and decision to opt to leave clinic was significant (p=0.000; OR12.082; CI (3.799-38.422)).

Table 4.18: Currently taking ARVS by If given a chance, would the patient opt to leave the clinic for another clinic

Patient currently taking ARVS	If given a chance, would you opt to leave this clinic for another?		Total
	Yes	No	
Yes	79 (82.3%)	17 (17.7%)	96 (100.0%)
No	5 (27.8%)	13 (72.2%)	18 (100.0%)
Total	84 (73.7%)	30 (26.3%)	114 (100.0%)

p=0.000; OR12.082; CI (3.799-38.422)

4.6.12 Currently taking ARVS by since patient stopped attending their appointment have they enrolled in another facility

According to Table 4.19, a significant number of patients (97.1%) who were currently taking ARVs had enrolled in another facility.

Table 4.19: Currently taking ARVS by since patient stopped attending their appointment have they enrolled in another facility

If yes above, are you currently taking ARVS?	Since you stopped attending your appointment in this facility, have you enrolled in another facility		Total
	Yes	No	
Yes	99 (97.1%)	3 (2.9%)	102 (100%)
No	3 (14.3%)	18 (85.7%)	21 (100%)
Total	**102 (82.9%)**	**21 (17.1%)**	**123 (100%)**

p=0.000; OR 198.000; CI (37.003-1059.469)

* cell less than 5

4.6.13 Patient still taking Septrin/Cotrimoxazole or Dabsone by where they collect their drugs when an appointment is skipped

Table 4.20 shows that many patients on Septrin/Cotrimoxazole or Dabsone (46.1%) had extra drugs to take when they skipped their appointment, while a big proportion (77.4%) of patients not on Septrin/Cotrimoxazole or Dabsone will take no action when they skipped their appointment. (Taking Septrin/Cotrimoxazole or Dabsone

had a significant statistical association to action taken by patient when they skipped the appointment).

Table 4.20: Patient still taking Septrin/Cotrimoxazole or Dabsone? by Where they collect their drugs when an appointment is skipped

Patient still taking Septrin/Cotrimoxazole or Dabsone	When an appointment is skipped, where patient collects drugs			
	Another facility	Just stay without	Had extra drugs to take	**Total**
Yes	29 (32.6%)	19 (21.3%)	41 (46.1%)	89 (100.0%)
No	4 (12.9%)	24 (77.4%)	3 (9.7%)	31 (100.0%)
Total	33 (27.5%)	43 (35.8%)	44 (36.7%)	120 (100.0%)

p=0.000

4.6.14 Still taking Septrin/Cotrimoxazole or Dabsone by if there times that the patient has not swallowed their ARVs

There was a low odds that those on Septrin/Cotrimoxazole would at times not swallow their ARVS (p=0.000; OR 0.068' CI (0.15-0.299) as indicated in Table 4.21.

Table 4.21: Still taking Septrin/Cotrimoxazole or Dabsone by if there times that the patient has not swallowed their ARVs

Patient still taking Septrin/Cotrimoxazole or Dabsone	Are there times patient has not swallowed their ARVs?		
	Yes	No	**Total**
Yes	54 (47.8%)	59 (52.2%)	113 (100.0%)
No	27 (93.1%)	2 (6.9%)	29 (100.0%)
Total	**81 (57.0%)**	**61 (43.0%)**	**142 (100.0%)**

p=0.000; OR 0.068' CI (0.15-0.299)

4.6.15 Still taking Septrin/Cotrimoxazole or Dabsone by if there are times that patient has not swallowed their Septrin

There was a low odds that those on Septrin/Cotrimoxazole would at times not swallow their Septrin (p=0.000; OR 0.87; CI (0.020-0.379)) as indicated by Table 4.22.

Table 4.22: Still taking Septrin/Cotrimoxazole or Dabsone by if there are times that patient has not swallowed their Septrin

Patient still taking Septrin/Cotrimoxazole or Dabsone	Are there times when patient has not swallowed their Septrin		
	Yes	No	Total
Yes	68 (58.1%)	49 (41.9%)	117 (100.0%)
No	32 (94.1%)	2 (5.9%)	34 (100.0%)
Total	100 (66.2%)	51 (33.8%)	151 (100.0%)

p=0.000; OR 0.87; CI (0.020-0.379)

4.6.16: Still taking Septrin/Cotrimoxazole or Dabsone by reason for not swallowing medicines

As indicated in Table 4.23, among the patients on Septrin/Cotrimoxazole or Dabsone, the main reason for not swallowing their medicine was forgetting.

Table 4.23: Still taking Septrin/Cotrimoxazole or Dabsone by reason for not swallowing medicines

	If yes above, what was the reason for not swallowing medicines?							
Patient still taking Septrin/Cotrimoxazole or Dabsone	Felt sick	Forgot to take	Had travelled	Felt better	Feared others would know my status	Out of supply	Others	Total
Yes	3(4.4%)	40(58.8%)	12(17.6%)	2(2.9%)	4(5.9%)	5(7.4%)	2(2.9%)	68(100%)
No	5(16.1%)	5(16.1%)	3(9.7%)	2(6.5%)	5(16.1%)	8(25.8%)	3(9.7%)	31(100%)
Total	**8(8.1%)**	**45(45.5%)**	**15(15.2%)**	**4(4.0%)**	**9(9.1%)**	**13(13.1%)**	**5(5.1%)**	**99(100%)**

p=0.001

4.6.17 Still taking Septrin/Cotrimoxazole or Dabsone by whether since patient stopped attending clinic appointment they enrolled in another facility

A significant number of patients on Septrin/Cotrimoxazole or Dabsone admitted they had enrolled in another facility (p=0.000; OR 109.250; CI (28.546-418.122) as shown in Table 4.24.

Table 4.24: Still taking Septrin/Cotrimoxazole or Dabsone by whether since patient stopped attending clinic appointment they enrolled in another facility

Patient still taking Septrin/Cotrimoxazole or Dabsone	Since you stopped attending your appointment in this facility, have you enrolled in another facility		
	Yes	**No**	**Total**
Yes	114 (95.0%)	6 (5.0%)	120 (100.0%)
No	4 (14.8%)	23 (85.2%)	27 (100.0%)
Total	**118 (80.3%)**	**29 (19.7%)**	**147 (100.0%)**

p=0.000; OR 109.250; CI (28.546-418.122)

* cell with less than 5

4.6.18 Use of alcohol or any other drug substances by where patients collected their drugs when an appointment was skipped

Table 4.25 shows that most patients (59.1%) who used alcohol or other drug substances, would just stay without their drugs when appointments were skipped compared to (40.5%) of the patients who did not use alcohol or any other drug substance who had extra drugs to take (p=0.048).

Table 4.25: Use of alcohol or any other drug substances by when an appointment was skipped from where patients collected their drugs?

Use of alcohol or any other drug substances	When you skip an appointment, where do you collect your drugs?			
	Another facility	**Just stay without**	**Had extra drugs to take**	**Total**
Yes	4 (18.2%)	13 (59.1%)	5 (22.7%)	22 (100.0%)
No	31 (27.9%)	35 (31.5%)	45 (40.5%)	111 (100.0%)
Total	**35 (26.3%)**	**48 (36.1%)**	**50 (37.6%)**	**133 (100.0%)**

p=0.048

4.6.19 Use of alcohol or any other drug substances by reason for not swallowing medicines

Forgetting to take the medicine was the most common reason given for not swallowing their medicine by both patients as shown in Table 4.26

Table 4.26: Use of alcohol or any other drug substances by reason for not swallowing medicines

	Reason for not swallowing medicines?							
Use of alcohol or any other drug substances	**Felt sick**	**Forgot to take**	**Had travelled**	**Felt better**	**Feared others would know my status**	**Out of supply**	**Others**	**Total**
Yes	1(4.8%)	10(47.6%)	0(0.0%)	3(14.3%)	1(4.8%)	5(23.8%)	1(4.8%)	21(100%)
No	9(10.2%)	36(40.9%)	17(19.3%)	1(1.1%)	7(8.0%)	13(14.8%)	5(5.7%)	88(100%)
Total	**10(9.2%)**	**46(42.2%)**	**17(15.6%)**	**4(3.7%)**	**8(7.3%)**	**18(16.5%)**	**6(5.5%)**	**109(100%)**

p=0.031

4.6.20 Use of alcohol or any other drug substances by whether patient found it easy to discuss you next appointment date with the clinician

According to Table 4.27, the proportion of patients who would find it easy to discuss their next appointment date with their clinician was lower in the patients who used alcohol or other drug substances compared to those who did not. The odds for the patient on alcohol or substance abuse finding it easy to discuss their next appointment with their clinicians was low compared to those not on alcohol or other drug substance (p=0.021; OR 0.208; CI (0.059-0.732).

Table 4.27: Use of alcohol or any other drug substances by whether patient found it easy to discuss you next appointment date with the clinician

Use of alcohol or any other drug substances	Do you find it easy to discuss you next appointment date with your clinician?		
	Yes	**No**	**Total**
Yes	13 (72.2%)	5 (27.8%)	18 (100.0%)
No	100 (92.6%)	8 (7.4%)	108 (100.0%)
Total	**113 (89.7%)**	**13 (10.3%)**	**126 (100.0%)**

p=0.021; OR 0.208; CI (0.059-0.732)

4.6.21 Use of alcohol or any other drug substances by getting a phone call from the clinic the day patient did not attend the clinic visit

As indicated in Table 4.28, Only (38.5%) of patients who use alcohol or any other drug substances got a call from the clinic the day they did not attend clinic, while (59.1%) of those who do not use alcohol or any other drug substance received a call from the clinic.

Table 4.28: Use of alcohol or any other drug substances by getting a phone call from the clinic the day patient did not attend the clinic visit

Do you take alcohol or any other drug substances?	Did you get a phone call from the clinic the day you did not attend your clinic visit?		
	Yes	**No**	**Total**
Yes	10 (38.5%)	16 (61.5%)	26 (100.0%)
No	81 (59.1%)	56 (40.9%)	137 (100.0%)
Total	**91 (55.8%)**	**72 (44.2%)**	**163 (100.0%)**

p=0.056; OR 0.432; CI (0.183-1.022)

Alcohol and substance abuse was not statistically significant to:

- The next time you visited the clinic after missing an appointment, how were you treated in the clinic? P=0.083
- If given a chance, would you opt to leave this clinic for another? P=0.190
- If you are not currently taking your ARVs and you had begun, what made you stop ?P=0.889

- For how long have you not attended a clinic visit in this facility? P=0.973
- What are reasons that made you stop coming for your clinic appointments in this facility? P=0.143
- Since you stopped attending your appointment in this facility, have you enrolled in another facility? P=0.088
- Do you have a treatment supporter? P=1.00
- Have you given your treatment supporters contacts to the clinic? P=0.387
- Has your treatment supporter asked to know how well you are taking your medication or attending your clinic visits? P=0.770
- Is your treatment supporter aware you have missed /stopped clinic appointments? P=1.000

4.6.22 Being in an HIV Support group by since patient stopped attending their appointment, had they enrolled in another

As indicated in Table 4.29, all patients in a support group (100%) had enrolled in another facility since the time they stopped their appointments. Of those patients who had joined but not active, (83.3%) had enrolled in another facility. Being in an HIV support group and enrolling in another facility showed a statistically significant association (p=0.024).

Table 4.29: Being in an HIV Support group by since patient stopped attending their appointment, had they enrolled in another facility

Are you in a HIV Support group?	Since patient stopped attending their appointment, had they enrolled in another facility		
	Yes	**No**	**Total**
Yes	21 (100.0%)	0 (0.0%)	21 (100.0%)
No	76 (73.8%)	27 (26.2%)	103 (100.0%)
Had joined but not active	15 (83.3%)	3 (16.7%)	18 (100.0%)
Total	**112 (78.9%)**	**30 (21.1%)**	**142 (100.0%)**

p=0.024

*cell with less than 5

The following variables did not show statistical significant when compared to HIV support group as shown in the above tables. One table had very few numbers to help in making any conclusion

- What are reasons that made you skip clinic appointment? p=0.251
- When you skip an appointment, where do you collect your drugs? p=0.228
- Are there times you have not swallowed your ARVs? p=0.133
- Are there times you have not swallowed your Septrin? p=0.182
- What was the reason for not swallowing medicines? p=0.342
- Did you get a phone call from the clinic the day you did not attend your clinic visit? p=0.897
- Do you find it easy to discuss you next appointment date with your clinician? p=0.489
- Would you opt to leave this clinic for another? p=0.872
- For how long have you not attended a clinic visit in this facility? p=0.882
- Do you have a treatment supporter? p=0.333
- Have you given your treatment supporters contacts to the clinic? p=0.105
- Has your treatment supporter asked to know how well you are taking your medication or attending your clinic visits? p=0.547
- Is your treatment supporter aware you have missed /stopped clinic appointments? p=0.120

4.623 Starting HIV clinics at facility by If given a chance, would patient opt to leave this clinic for another

Many of the study patients (77.8%) who had started HIV clinic at the facility admitted that given the chance they would opt to leave for another clinic. There was a higher odds for a patient who had started the HIV clinic at the facility opting to leave (p=0.057; OR 2.471; CI (1.056-5.780) as shown in Table 4.30.

Table 4.30: Starting HIV clinics at facility by If given a chance, would patient opt to leave this clinic for another

Did you start your HIV clinics in this facility?	If given a chance, would you opt to leave this clinic for another?		
	Yes	**No**	**Total**
Yes	98 (77.8%)	28 (22.2%)	126 (100.0%)
No	17 (58.6%)	12 (41.4%)	29 (100.0%)
Total	**115 (74.2%)**	**40 (25.8%)**	**155 (100.0%)**

p=0.057; OR 2.471; CI (1.056-5.780)

CHAPTER FIVE

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Discussions

5.1.1 Socio-demographic factors

In this study, a higher proportion of female than male (ratio 2:1) was lost to follow up. This finding corresponds to results of the Kenya AIDS Indicator Survey that indicate that more women 6.9% than men 4.4% were HIV infected (KAIS, 2012). This finding was similar to previous studies carried out in West Africa, Lesotho, Tanzania and Kenya where women bear a higher burden of HIV infections than men (Sanne *et al*., 2015, Sia et al., 2014, Beyrer et al., 2013). The higher proportion of Lost to follow up female patients may be due to their higher infection numbers compared to male patients. This could further be explained by the fact that acquisition and prevention of HIV infection in women is complex and influenced by biological, behavioral and structural factors.

Marital status in this study was comparable with most studies in similar settings, where a higher proportion of patients were married, 67.1%. A study in West Africa reported 52% of participants being married or partnered in a relationship like marriage (Sanne *et al*., 2015) and a similar study in Uganda reported 54% were married (Opiyo *et al*., 2019). Being married has been documented to increase the risk of heterosexual transmission of HIV particularly in sub-Saharan African settings where gender inequalities and high levels of background HIV prevalence combine to make married individuals susceptible to HIV infection (Nabukenya *et al*., 2020)

Most patients had Primary level of education consistent with a study evaluating retention in HIV care in Uganda and Kenya where 79% and 75% of men and Women in the study had primary level education (Brown *et al*., 2019). A study in India on factors associated with attrition, mortality, and loss to follow up after antiretroviral therapy initiation found that patients with no education were more likely to be LTFU (Alvarez *et al*., 2013). Similar findings were found in Nigeria and China (Meloni *et*

al 2014; Tang *et al.,* 2015) .The findings contrast those of a study in South Africa on relationship between on Socio-economic status where most of the patients had completed secondary education (Bunyasi *et al*., 2017). Patients who are less educated may not be able to read and understand text messages and some shy away from responding and expressing themselves often missing the support they may need from Health Care Workers. The difference in findings may have been due to study settings, the study was done in a public hospital in a rural-urban setting.

Concerning employment, an employee may not want to be seen to miss work as often as sometimes the appointments demand. In the Kiambu CRH CCC clinic, at the time of study, there was a practice of giving short return dates on appointment once a patient skipped a scheduled appointment, this may have complicated adherence to clinic appointments although its intention was quality improvement when dealing with unscheduled appointments.

5.1.2 Patient Related Loss to follow up Factors

In this study, most of the participants accepted their HIV positive status, this indicated that they understood the HIV infection and were not in denial that they were positive. As part of treatment preparation education, all patients in Kiambu CRH CCC are taken through three counseling sessions before enrollment, some of the information given is on acceptance of HIV status and this could explain the 95.2 % disclosure outcome in the study. This could be seen as the beginning of the treatment journey that enables the health care workers to start the lifelong treatment to the clients, however, the fact that this study found a high level of acceptance of status among LTFU patients may indicate that this acceptance may be routine and not well understood by the patients. Six percent (6%) of patients in this study who had not accepted their status is a significant proportion given that HIV is a public health threat.

Ninety five percent of patients interviewed had disclosed their HIV status to someone, majority being to the partner or a close relative, 94% (n=289) of patients reported that they had accepted their HIV status. The findings of the study are in line with previous research on review of social and gender context of HIV disclosure in

Sub-Saharan Africa that found disclosure rates to be >74% despite the complex nature of the disclosure process (Bott *et al*., 2013). Similar rates have been reported in Mali, Burkina Faso, DRC and Uganda (Ssali *et al*., 2010, Msumari *et al*., 2014). A study in rural Ethiopia found disclosure to be statistically significant in predicting LTFU (Tamrat *et al*., 2015). According to the study, those who did not disclose to family members had nearly three times risk of LTFU compared to those who disclosed. In another study on perceived stigma and discrimination towards people living with HIV and AIDS in Ethiopia, disclosure was not found to be significantly related to LFTU (Asgary *et al*., 2013). In Kiambu County Referral Hospital, a patient is required to disclose to at least one person as they are enrolled into care or at least within the first three months of care. The emphasis to disclose is made on every visit. It is also required that the patient provides contacts of a person they have disclosed to, this person is referred to as a treatment supporter and can be contacted incase the clinic was unable to reach the patient on phone regarding information related to care and treatment. On disclosure of status to others, clients who do not disclose their status could be perceived as less likely to receive social support and therefore expected to perform poorly in achieving optimum levels of adherence and retention in care.

How long a patient had not attended clinic was in this study associated significantly with duration since client knew their status, with those who had attended clinic for less than 12 months being more likely to be lost to follow up. This finding is consistent with various other studies, which reported that a large proportion of patients dropped-out from care within the first year of ART. A study in Ethiopia on predictors of Loss to follow up found that the probability of attrition from care was directly associated with the length of engagement with ART care, a higher proportion of LTFU was recorded in the first 6 months after ART initiation (Berheto *et al*., 2014). The first year in HIV treatment is seen as a crucial time for treatment literacy and preparation for clients on their life long treatment with ARVs (Assefa *et al*., 2011).

On alcohol and other drugs substances among the Lost to follow up clients, most patients (59.1%) who used alcohol or other drug substances, would just stay without

their drugs when appointments were skipped. The odds for the patient on alcohol or substance abuse finding it easy to discuss their next appointment with their clinicians was low compared to those not on alcohol or other drug substance (p=0.021; OR 0.208; CI (0.059-0.732). Only (38.5%) of patients who use alcohol or any other drug substances got a call from the clinic the day they did not attend clinic, compared to (59.1%) of those who do not use alcohol or any other drug substance. A study in Wakiso District, Uganda found that men with greater scores on the alcohol frequency and quantity index were more likely to report missed pills compared to those reporting no drinking (AOR: 1.60, 95% CI: 1.29–1.97)(Katelyne *et al* 2019). Similarly, a systematic review of the impact of alcohol use disorders on HIV treatment outcomes, adherence to antiretroviral therapy, and health care utilization found that alcohol use disorder in people living with HIV/AIDS is linked with non-adherence to antiretroviral therapy, decreased help-seeking and health care utilization as well as poor HIV treatment outcomes (Azar *et al*., 2010). Although this study did not categorize the type of substances used, a study on use of cocaine and multiple substances were significantly related to decreased HIV medication adherence for Injecting Drug Users.

On support groups, the current study found that all patients in a support group (100%) had enrolled in another facility since the time they stopped their appointments. Of those patients who had joined but not active, (83.3%) had enrolled in another facility. Being in an HIV support group and enrolling in another facility showed a statistically significant association (p=0.024). HIV programs use support groups as an opportunity for health care workers and trained HIV positive volunteers to provide information and to address the special needs of fellow PLHIV and their partners. Such groups serve the purpose of sharing experiences, encouraging disclosure, reducing stigma and discrimination, improving self-esteem, enhancing patients' coping skills and psychosocial functioning and supporting medication adherence and improved retention in HIV care. A 20 studies review in South Africa on impact of support groups from low- and middle-income countries which evaluated the impact of support groups on retention in care found positive benefits associated with support group membership including enhancing treatment success (Mutambo *et al*., 2012). Similarly, another study found that 89.9% of support group members

reported that support group meetings helped create a forum for sharing knowledge and experiences, some of which related to taking medications. In Mozambique PLHIV enrolled in support groups reported increased adherence (Decroo *et al*., 2011).

5.1.3 Hospital Factors

The study found that Kiambu County Referral Hospital CCC was prompt in initiating clients to ARVS (75.7%) and to Cotrimoxazole/Dabsone (99.4%). Nearly all clients had been taken through counselling on ARVs and Cotrimoxazole or Dabsone, which is the recommended prophylactic treatment for opportunistic chest infections common to immunosuppressed patients. This was consistent with Ministry of Health guidelines on HIV prevention and treatment standard protocols that recommended all clients to receive counselling on ARV life- long treatment and to start on treatment within two weeks of enrollment into the program (NASCOP, 2011).

While 89.1% indicated to have started their HIV clinics at the study Hospital, 74.2% would opt out of the Kiambu referral county hospital given the option, the main reason, 61.3% being long queues while a third were made to wait if one had missed an appointment. A study in Uganda on barriers to accessing highly active antiretroviral therapy was consistent with the findings that long waiting times at health facilities generally reflect the human resource constraints pervasive in busy ART clinics in sub-Saharan Africa (Duff *et al*., 2010). Similarly, long waiting times have been mentioned as a key driver in the attrition of clients on ART in a Sub-Saharan systematic review on barriers to retention further noted that competing activities such as work and social life among clients seeking medical attention tend to interfere with time spent queuing in overburdened health facilities (Decroa *et al*., 2013). Long queues are an indication of gaps in health systems management that include health care providers training, infrastructure, health information management and quality assurance and control. Time taken to see a patient could largely depend on capacity of the health care provider to make decisions; this was not explored in this study.

Clients stop attending clinic due to various reasons, the main reasons given for lost to follow up in this study was transfer out of the facility of study self- transferred out, relocation to other places of residence and some Lost to follow up patients had already died by the time of this study. Nineteen percent of patients classified as LTFU reported that they had transferred out from the facility following the right procedures. Verification of the transfer was done through chart abstraction and information was found on the patients clinical notes. This may be indicative of challenges with data capturing and proper documentation of patient management decisions by data managers and clinicians. A study from Malawi noted poor documentation to be among top reasons that explain why patients may become LTFU (Shaweno, *et al*., 2015). Another study evaluating outcomes of LFTU in a large comprehensive clinic in Western Kenya agrees that poor documentation had some patients incorrectly labeled as LFTU. In this study, a significant proportion of patients who were originally considered LFTU later confirmed to have transferred out to other facilities where they continued with care and treatment and therefore, undocumented patients may have transferred to other clinics and thus are only LFTU from the perspective of their original clinic (Rachlis *et al*., 2015).

Complications of HIV may cause death while patients who are on HIV treatment may also die of other causes, dead patients should be classified correctly as dead and not as LTFU. This study found out that 12.7% of the patients who had been classified as LTFU were actually dead. These deaths may have occurred at home or in other health facilities while others may have occurred in the study facility and were not documented at the Comprehensive clinic, possibly due to the weak link between the hospital inpatient wards and the CCC clinic in terms of patient tracking. Weaknesses in patient tracking in the community and inpatient wards have implications both to the County and national programs in areas of reliable vital statistics. A study conducted in South Africa had consistent findings that death of the patients was the second most frequent reason for loss to follow-up after poor documentation (Maskew *et al*., 2007). Updating patients' database on death is important for accurate data.

Self-Transfer out patients continue to be seen as LTFU until the clinic verifies with the receiving facility that they are enrolled for care and treatment. Once verified,

information should be updated on the electronic data indicating the patients current follow up status. In this study, 15.3% of respondents reported that they had transferred themselves from the study facility to other facilities. Self- transfer-outs point to weaknesses in the patient referral system and implies weak communication links between the different ART sites. Some cases of self- referrals in this study may have been due to the patients admitted in the hospital wards and initiated on ART while in the ward actually come from far-away places from the ART initiation point. On recovery and discharge from the ward, they decide to transfer themselves to the ART sites nearest to them without informing the initiating site. Besides affecting proper classification of patient outcome, self-transfers could also affect accurate drug forecasting at facility level in respect of both ARVs and drugs for opportunistic infections. A self-transfer patient could compromise their treatment outcomes by receiving an inferior treatment regimen than what they were taking. A meta-analysis review on Self-Transfer and mortality among adult patients in ART programs in low and middle income countries found that almost one in five ART patients initially reported as LTFU had self-transferred and were active in care in other facilities (Wilkinson *et al*., 2015).

5.1.4 Adherence to treatment among LTFU patients

Forgetting to take the medicines was the most common reason for non-adherence to medication among the clients on ARVs and or septrin/Cotrimoxazole or Dabsone in this study. There are scanty studies on continuation on ARVs and other preventive medicine for patients lost to follow up this could be largely because patients lost to follow up are seen as disengaged from treatment, from this study, it is evident that a significant number of patients continue with care and treatment elsewhere while lost from the initial linked-to facility.

On adherence to treatment among lost to follow up patients the study found a self-reported adherence to ARVs of 39.6%. This adherence was higher than what was expected given that these clients were lost to follow up from the clinic at the time of study. This could indicate that patients increasingly understand the importance continuation of treatment and are actively engaged in their care despite

communication challenges between the facility and clients. A study in Western Kenya corroborates with our finding that patients incorrectly labelled as LTFU in one facility were found to be actively continuing with care and treatment in other facilities (Rachlis *et al*., 2015).

5.2 Conclusions

Despite the justification of any reason, loss to follow up is a sad disconnection to the linkage and retention for the full realization of the intended patient assisted intervention programs (such as distribution of ARVs) whose intentions are to reduce the suffering and pain and subsequently prolong life for HIV positive patients. Based on quantitative analysis it can be concluded that disclosure of HIV status, having a treatment supporter and being in a support group were positively associated with remaining engaged in care while long queues and alcohol consumption were negatively associated with clients retention into care.

Patients understand that continuation of care is important for their well-being; patients already started on ARVs are likely to seek care in other facilities of choice although the study showed that current facility did not receive communication from the clients. Having started on ARVs and or Septrin was associated with re-engaging into care for LTFU clients while those not started were likely not to seek care elsewhere.

Duration of time since when client learnt their HIV status was identified as an important factor in that the risk of becoming LTFU increased with duration of time client learnt their HIV status. Health education and counselling on importance of adherence to treatment remains as important to older clients as to new clients.

Long Queues for clients on treatment upon returning to the clinic after missed appointments resulted to opting for another facility. Competing schedules requiring clients' time need to be considered against the total time taken by a client at the clinic to mitigate against LTFU.

The study identified outcomes for a high proportion of clients reported to be LTFU. Importantly, it found that a proportion of patients initially identified, as LTFU were not actually lost, they were either self-transfers or legitimate transfers, indicating the importance of maintaining up-to-date information on patient status as well as the need for accurate details on visit history and patient locations to assist with timely tracing. Besides affecting proper classification of patient outcome, self- transfers could also affect accurate drug forecasting at facility level in respect of both ARVs and drugs for opportunistic infections. Patients have the willingness to continue with care and treatment and proper documentation and facilitation of transfers will reduce the patients classified as LTFU and improve the quality of data and decision-making. National programs rely on facility data for programming and policy formulation and therefore the need to ensure data accuracy.

Health care workers should pay more attention to patients who have not disclosed their status, those who consume alcohol and those not in support groups as they remain at a high risk of disengaging from care.

5.3 Recommendations

Utilize an appointment system that considers and reduces overall time taken by clients at the HIV clinics. Discouraging clients from attending their clinic appointments, long queues were associated with negatively affecting continuation of care.

Develop and implement Standard Operating procedures on patient flow at the HIV clinic and explore capacity gaps among the health care providers to provide specific continuing education.

Reminder system on treatment would be helpful to clients on ART given that the main reason identified in this study for non-adherence among the LTFU was forgetting to take the drugs.

Clients intention to stop attending clinic or transferring to another clinic should routinely be screened to allow for timely interventions. Further, strengthening

communication and transfer mechanism between transferring and receiving ART sites with reliable feedbacks on every patient transfer, whether facility initiated or self-transfer be given priority in order to help account for every patient.

There is need to improve documentation of patient information especially with the new Electronic Data System to improve and strengthen information flow between the various hospital wards and the CCC on one hand and the CCC and the community structures on another and to properly capture information relating to deaths and/or complications in respect to admitted and discharged patients. It is recommended that hospital phone numbers be made known to patients and their supporters and further educate them on timely communication regarding patients' mobility, change of addresses, self- transfers or death.

Due to the high proportion of "the untraceable' clients (45%) among the group of clients originally classified as LTFU, this study recommend strengthening of collection and updating of patients contacts useful for tracing clients who fall into LTFU group.

Future research could explore more on how to improve coordination between clinics when there are transfers involved. Related to this is the need to capture details on deaths as they occur, to correct mortality and LTFU estimates. The findings of this study have implications for the development and implementation of health care delivery and outreach program models that acknowledge patient realities and needs.

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APPENDICES

Appendix I: Information Sheet (English Version)

Tittle: **FACTORS ASSOCIATED WITH LOSS TO FOLLOW UP AT KIAMBU COUNTY REFERRAL HOSPITAL, FOR PATIENTS LIVING WITH HIV**

My name is Florence Kaara. I am Masters Student in Public Health from JKUAT. You are invited to take part in research about missed appointment from comprehensive care clinic in Kiambu County Referral hospital. We ask that you read this form before agreeing to be in the research. If you cannot read, you can request the researcher to read it to you.

Purpose

The purpose of the research is to find out factors that affect HIV patients' retention and defaulter rates in Kiambu District Hospital which would inform the hospital management on strategies that would help address these factors and therefore reduce care and treatment defaulters.

Procedures

If you agree to be in this research, and sign this consent form, my assistant or I will describe the questions you will be asked including their purpose. The questions should take only 20 - 30 minutes of your time.

Risks and Benefits

There are no direct benefits to you of the study. The risk level of this research is considered less than minimal.

Confidentiality

The records of this study will be kept private. Anything you tell us will remain confidential. In any sort of report of the study, we will not include any information

that will make it possible to identify you. We are not asking for your name, address, or phone number. Your name and other identifying information will not be kept with this survey. The surveys will be kept in a locked file; only the researchers for this study will have access to the records.

Voluntary nature of study

Your decision whether or not to participate will not prejudice your future relations with Kiambu District Hospital, Kenya Medical Research Institute, Jomo Kenyatta University of Agriculture and Technology and staff helping with this study. If you do not wish to take part or you do not want to answer some of the questions, you do not have to give us a reason. Even if you sign the consent form, you are free to stop at any time. You do not need to complete it if you feel uncomfortable doing it.

Contact

The researchers conducting this study are Florence Kaara and her assistants. You may contact the researchers at any time. Questions regarding the rights of research subjects may be directed at the Ethical Committee at the Kenya Medical Research Institute.

In case of any queries or concerns, please contact the chief researcher Principal investigator or KEMRI on:

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Appendix II: Information sheet (Kiswahili Version)

FOMU YA MAELEZO KUHUSU IDHINI

FOMU YA MAELEZO KUHUSU IDHINI

Kwa muhisika,

Jina langu ni Florence Kaara. Mimi ni mwanafunzi katika chuo kikuu cha Jomo Kenyatta ambapo ninanuia kuhitimu na shahada ya juu ya Public Health. Nafanya utafiti wa nini husababisha wagonjwa kutofuatilia kliniki za matibabu ya HIV na AIDS. Utafiti huu umeidhinishwa na kamati ya maadali ya utafiti na meneja mkuu wa hosipitali ya Kiambu.

Ili kupata habari kuhusu swala ninalo tafitia, nimeuda fomu ya maswali. Ombi langu kwa kunyanyekea ni kuwa utashiriki kwa kujibu maswali yaliyoko katika fomu hii kwa kujitolea na tena kwa ukweli. Kushiriki kwako kutakuwa kwa hiari yako na hakuna adhabu kwa kudinda kushiriki. Hakuna hatari ya kushiriki katika utafiti huu. Majibu yako katika fomu itashughurikiwa kwa siri kama ilivyoruhusiwa kisheria. Huhitajiki kuandika jina lako au kitambulisho cha aina yoyota katika fomu hii. Unaruhisiwa pi kujitoa katika utafiti huu katika hatua yoyote bila hofu ya uonevu.

Matokeo ya utafiti huu yatasaisia madaktari kuweka mikakati sahihi ya kupunguza kupotea kwa wagonjwa wa kliniki ya HIV na kuzindisha ufuataji wa kliniki zao kama wanavyopanga na madaktari . Ikiwa utataka kujua matokeo ya utafiti huu, una haki ya kupata. Unaweza kuuliza maswali yoyote kuhusiana na haki yako kama mshiriki au kitu kingine chochote kuhusu utafiti huu ambacho unahisi si wazi. Shukrani kwa kukubali kushiriki.

Ikiwa una maswali, maoni au mapendekezo yoyote au ufafanusi jisikie huru kuwasiliana na mpelelezi mkuu kwa habari ya simu 0722 615 397

Asante

Florence Kaara (mtafiti)

Appendix III: Consent Form (English Version)

Title: FACTORS ASSOCIATED WITH LOSS TO FOLLOW UP AT KIAMBU COUNTY REFERRAL HOSPITAL, FOR PATIENTS LIVING WITH HIV

Principal Investigator: Florence Kaara

Dear client,

You are invited to participate in the above research project. The **study is a partial fulfillment of requirements of a masters program in Public Health**.

The Scientific Review Board approved the study and its procedures. The study involves no foreseeable **risks** or harm to you. The **procedure** includes filling of a structured questionnaire.

You are free to ask **any questions** about the study or about being a participant by calling me at 0722615397 or e-mail: kaaraflorence@gmail.com.Your participation in this study is **voluntary**; you are under no obligation to participate. You may **withdraw** at any time. By returning the completed questionnaires implies consent for participating in the study. To maintain anonymity, please do not write your name on any of the materials.

The completed study will be reported in the aggregate. **Confidentiality** will be maintained. All data will be collected by trained assistants, stored in a secure place and will be destroyed in three years.

I have read the above information and understand that this survey is voluntary and I may stop at any time. I consent to participate in the study.

_____ _____

Signature of participant Date

_____ _____

Signature of researcher/ research assistant Date:

_____

If your participation in our survey has caused you to feel uncomfortable in any way, or if our survey prompted you to consider personal matters about which you are concerned, we encourage you to take advantage of the confidential counseling services offered at the University health center.

Appendix IV: Consent Form (Kiswahili Version)

Fomu ya ridhaa ya kushiriki utafiti

Kichwa cha mradi: Mambo yanayo athiri viwango vya wagonjwawa VVU kushikiliana kuzingatia matibatu katika Hospitali ya Wilaya ya Kiambu

Kanuni Mpelelezi: Florence Kaara

Ndugu mteja,

Wewe niwalioalikwa kushiriki katika mradi huu wa utafiti. Utafiti ni wakutimiza sehemu ya mahitaji ya Shahada ya juu ya Public Health.

Ethical Review Board imepitisha utafiti nataratibu zake. Utafiti hausababishi hatari zozote au madhara kwako. Utaratibu ni pamoja na kujaza dodoso muundo.

Wewe nihuru kuuliza maswali yoyote kuhusu utafiti au juu ya kuwa mshiriki kwa kupiga simu yangu 0722615397 au barua pepe kwa: kaaraflorence@gmail.com.

Kushiriki kwako katika utafiti huu ni kwa hiari; Hauko chini yawajibu wowote kushiriki. Unaweza kuondoka wakati wowote. Ili kudumisha kutokujulikana, tafadhali usiliandike jina lako kwenye vifaa vyovyote.

Utafiti utakapo kamilika utakubalishwa kutazama ripoti yake. Usiri utasimamiwa. Data zote zitakusanywa na wasaidizi mafunzo, kuhifadhiwa katika mahali salama na zitaangamizwa baada ya miaka mitatu.

Nimesoma na kuelewa maelezo yote katika fomu hii kuhusu utafiti unaofanywa na nimekubali kwa hiari yangu kushiriki.

Sahihi ya mhusika……

Tarehe……..

Mtafiti……..

Tarehe……..

Appendix V: Questionnaire

Questionnaire No._____ Patient Unique No. _____

Defaulter: ☐

Lost To Follow Up: ☐

Introduction

Please answer the questions below using the instructions given. You are kindly requested to feel free as you put your contribution. There is no right or wrong answers to the questions.

Social demographic and economic information

1. Sex

    1. Male
    2. Female

2. What is your age? (completed years)

    1. 16 to 25 years
    2. 26 to 35 years
    3. 36 to 50 years
    4. 51 to 65 years
    5. 66 and above years

3. What is your highest completed level of education? (Tick one)

    1. None

    2. Primary

    3. Secondary

4. Tertiary

4. Are you married?

    1. Yes
    2. No

5. If yes above, what is your marital status? (Tick appropriate)

    1. Married to one partner
    2. Married to more than one partner
    3. Divorced/ separated
    4. Widowed

6. What is your present occupation? (Tick appropriate)

    1. Employed
    2. Self employed
    3. Unemployed
    4. Casual Labour
    5. Other (specify)

7. What is the ownership of the house you live in? (Tick appropriate)

    1. Rented
    2. Own house
    3. Others specify _____

8. In what type of a house do you live in? (Tick appropriate)

    1. Permanent
    2. Semi-Permanent
    3. Temporally

9. What is the size of the house you live in?

    1. One room
    2. Two rooms
    3. >Two rooms
    4. Self-contained house

10. How many people depend on you financially?
    1. None
    2. One
    3. Two
    4. Three
    5. More than Three _____

Factors associated with Missing scheduled appointment and LTFU

11. When did you learn your HIV status?

    1. 0 to 12 months ago
    2. 1 year to 2 years ago
    3. More than 2 years ago

12. Have you accepted your HIV status?

    1. Yes
    2. No

13. Have you disclosed your HIV status to anyone?

    1. Yes
    2. No

14. If yes above, please indicate to whom you have disclosed?

    1. Partner
    2. Friend

3. Sibling (Brother, sister)
4. parent

15. Have you ever been started on ARVs?

1. Yes
2. No

16. If yes above, are you currently taking ARVS?

1. Yes
2. No

17. If yes above, when did you start? (Month and year)

_____month _____year

18. Did you start your HIV clinics in this facility?

1. Yes
2. No

19. Have you ever been started on Septrin/ Cotrimoxazole?

1. Yes
2. No

20. If yes above, are you still taking Septrin?

1. Yes
2. No

21. When you enrolled into this clinic, were you counselled about how to take your Septrin and or ARVs?

1. Yes
2. No

3. Don’t Know

22. Do you take alcohol or any other drug substances?

1. Yes
2. No

23. Are you in a HIV Support group?

1. Yes

2. No

3. Had joined but now inactive

Missed appointment factors

24. What are reasons that made you skip clinic appointment?

1. Felt ill
2. Felt better
3. Forgot
4. Was working
5. Lack of bus fare
6. No reason
7. Others (specify)

_____

25. When you skip an appointment, where do you collect your drugs?

1. Another facility
2. Just stay without

26. Are there times you have not swallowed your ARVs?

1. Yes

2. No

27. Are there times you have not swallowed your Septrin?

1. Yes
2. No

28. If yes above, what was the reason for not swallowing medicines?

1. Felt sick
2. Forgot to take
3. Had travelled
4. Felt better
5. Feared others would know my status
6. Others (specify)

29. Did you get a phone call from the clinic the day you did not attend your clinic visit?

1. Yes
2. No

30. Do you find it easy to discuss you next appointment date with your clinician?

    1. Yes
    2. No

31. The next time you visited the clinic after missing an appointment, how were you treated in the clinic? Tick all that are appropriate

    1. Welcomed warmly
    2. Made to wait longer before been seen by clinician
    3. Was quarreled
    4. Was talked to by a counsellor on taking my drugs and attending clinic on time.

5. Others (specify)

32. If given a chance, would you opt to leave this clinic for another?

1. Yes
2. No

33. If yes above, please give reasons why you would opt for another clinic

_____

34. If you are not currently taking your ARVs and you had begun, what made you stop?

1. Felt better
2. Felt sick
3. Travelled
4. Did not pick drugs
5. Doctor stopped me
6. Others (specify)

35. For how long have you not attended a clinic visit in this facility?

1. 90-119 days

2. 4-6 Months _____

3. 7-12 Months _____

4. More than12months_____

36. What are reasons that made you stop coming for your clinic appointments in this facility?

1. Felt better
2. Lack of bus fare
3. Permission from place of work
4. Relocated

5. Health Care providers attitude

37. Since you stopped attending your appointment in this facility, have you enrolled in another facility

    1. Yes
    2. No

38. Do you have a treatment supporter?

1. Yes
2. No

39. Have you given your treatment supporters contacts to the clinic?

1. Yes
2. No

40. Has your treatment supporter asked to know how well you are taking your medication or attending your clinic visits?

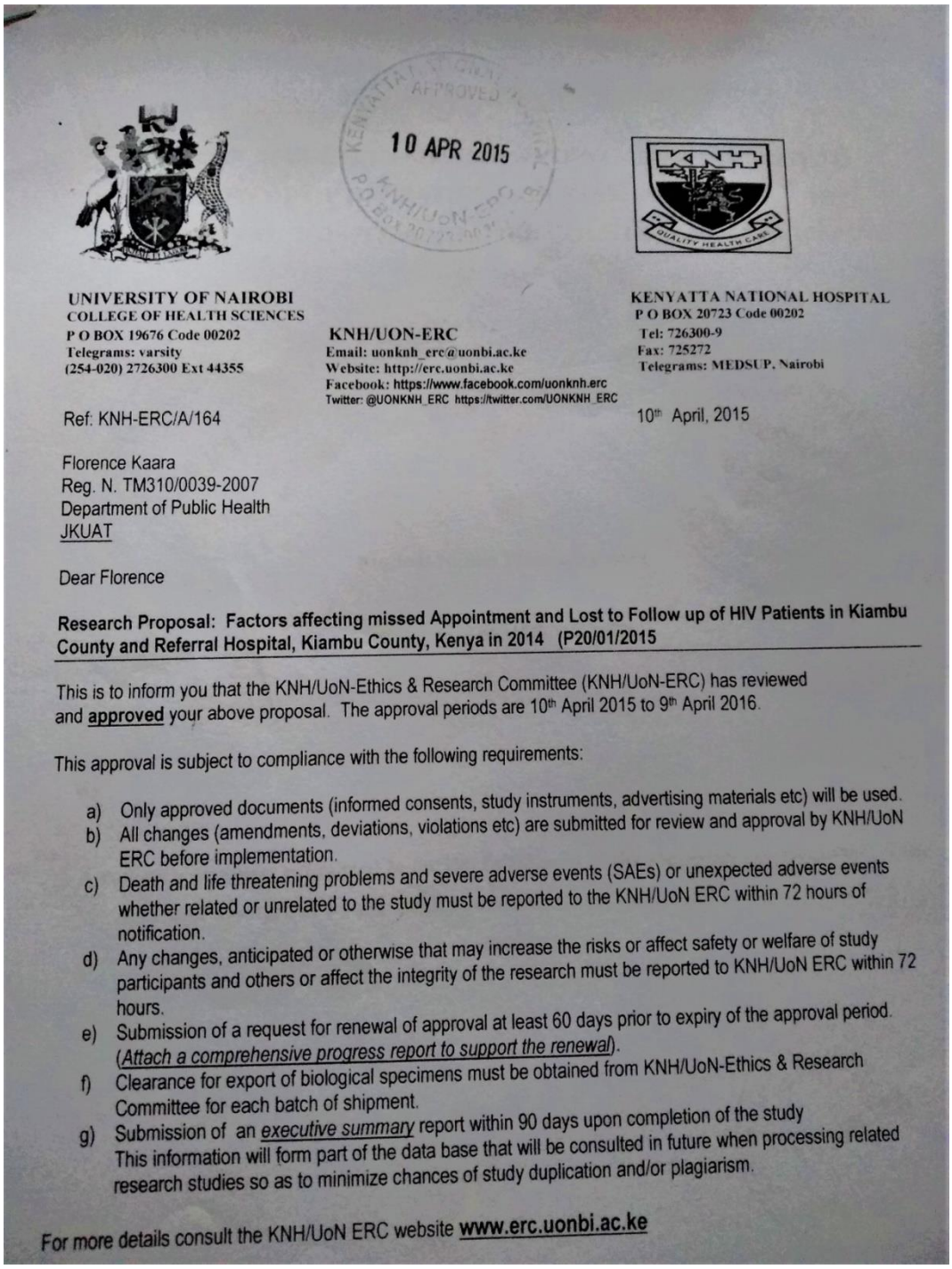
    1. Yes ___
    2. No ___

41. Is your treatment supporter aware you have missed /stopped clinic appointments?

1. Yes___
2. No ___

Thank you for your time

Appendix VI: Ethical Approval letter by KNH/UoN Ethical Review Committee



10 APR 2015

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Ref: KNH-ERC/A/164

10th April, 2015

Florence Kaara
Reg. N. TM310/0039-2007
Department of Public Health
JKUAT

Dear Florence

Research Proposal: Factors affecting missed Appointment and Lost to Follow up of HIV Patients in Kiambu County and Referral Hospital, Kiambu County, Kenya in 2014 (P20/01/2015

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above proposal. The approval periods are 10th April 2015 to 9th April 2016.

This approval is subject to compliance with the following requirements:

a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
c) Death and life threatening problems and severe 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.
d) 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.
e) 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*).
f) Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
g) Submission of an *executive summary* report within 90 days upon completion of the study This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

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

Appendix VII: Publication

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1

FACTORS ASSOCIATED WITH LOSS TO FOLLOW UP OF ADULT PATIENTS LIVING WITH HIV IN KIAMBU COUNTY AND REFERRAL HOSPITAL, KIAMBU COUNTY, KENYA

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ABSTRACT

Purpose: The main objective of this study was to determine the factors associated with loss to follow up and its effects on treatment adherence among HIV positive patients in Comprehensive Care Clinic in Kiambu County Referral Hospital, Kiambu County.

Methodology: This was a descriptive cross sectional study conducted in Kiambu County referral hospital. HIV positive adult patients enrolled in care and documented to have been lost to follow up according to case definition were recruited as participants. A list was generated from the facility's database to calculate a sample size of 327. Random sampling was used to get patients who met the inclusion criteria. Structured questionnaires administered to participants were used and resultant data was coded, cleaned, sorted and analyzed using Statistical Package for Social Sciences version 17. Participants were called on phone to the hospital Comprehensive care clinic and those not reachable on phone residing within the catchment area were visited in their homes.

Results: The study found that a third all patients could not be traced by the phone call to the patients or to the treatment supporter or by physical home visit and could therefore their true status was not identified. A proportion of 12.9% classified as lost to follow up were actually dead while 4.3% of files of patient classified as lost were not physically found in the hospital records. Those who were confirmed alive were 69.6% from whom 25.5% had discontinued with care, 41.6% had transferred out and 32.9 % had self-transferred to other facilities where they were continuing with care. The rate of LFTU was found to be 16% against a target of a 10% maximum rate. There is the need to strengthen mechanisms to capture details on deaths as they occur, improve linkage to other facilities, improve on documentation of all patient data including contact and transfer details.

Key words*: Lost to Follow Up, Transfer out, dead, Self- transfer out.*