

**THE FACTORS AFFECTING RETENTION IN CARE OF PATIENTS ON  
ANTIRETROVIRAL TREATMENT IN BUSHENYI DISTRICT;  
A CASE STUDY OF HIV CLINIC KAMPALA  
INTERNATIONAL UNIVERSITY,  
TEACHING HOSPITAL**

**BY**

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### **Declaration**

I Listern Tenga Tenga hereby declare that this research report has been done by me according to the research regulations of Kampala International University and that it has not been submitted to any other institution of learning for award of any qualification.

Signature.....

Date.....

**Listern Tenga Tenga**

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### **Approval**

I affirm that this research report titled “factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District” is being supervised in accordance to the plans of supervision of research report laid down by Kampala International University.

Signature: ..... Date .....

**Prof. Kim**

## **Dedication**

This research report is dedicated to my beloved my parents, brothers and sisters and all my friends who have always backed me throughout the course of my study.

## **Acknowledgement**

I am so grateful to the almighty God for the gift of life he has endured to me and his guidance in this course.

I also acknowledge the support, guidance and pieces of advice from my beloved parents which has guided me through the course. I am also grateful to my brothers and sisters and my friends who have always encouraged me whenever I would loose hope. I am really so grateful for everyone' support.

Finally, I appreciate the wisdom and guidance of my research supervisor Professor Kim who is guiding me through this research study.

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## **Abstract**

The study was to assess the factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District using KIU-TH as the case study. The study was guided by three objectives i.e. to find out the economic factors affecting retention in care of patients on antiretroviral treatment in KIU-TH, to assess the social factors affecting retention in care of patients on antiretroviral treatment in KIU-TH and to examine the health system factors affecting retention in care of patients on antiretroviral treatment in KIU-TH. A cross-sectional research design was used for this study; the researcher studied 112 respondents, simple random sampling technique was used to select patients/clients and purposive sampling was used to select health workers because they had prior knowledge on the topic; Questionnaires to collect data from the clients and interview guides to collect data from the health workers. Data was also analyzed using Excel and SPSS version 16.0 i.e. bivariate analysis was performed using chi-square and p-value and graphs that aided in discussion of the findings.

The study found out that the retention of KIU-TH HIV clinic was 68% in February 2019; the factors that affected patient retention in care were particularly long distance to ART center, cost of transportation and high patient load with long waiting times at the clinic represented the greatest barrier to accessing treatment, excessive drinking of some patients, HIV related- stigma and non-disclosure of HIV status to sexual partners and families are significant barriers and shortage of health personnel. However, if the needs of patients are to be met, systems in health facilities need to be strengthened to reduce loss to follow up, increase adherence and promote long term retention.

From the study findings, the researcher recommended that patients need to be continually encouraged to take treatment at their nearest treatment center. He also suggested that health care providers including adherence support workers should take an active role in the fight against stigma. Strategies that can encourage patients to improve on disclosure of HIV status should be developed. The researcher recommended that different appointments should be given to the patients to minimize the health personals workloads.

## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.0 Introduction**

This chapter presents the background to the study, statement of the problem, objectives, the research questions, scope, significance of the study and conceptual framework.

#### **1.1 Background**

HIV/AIDS remains a major public health problem across all continents, causing the death of millions of adults in their prime, disrupting and impoverishing families and turning millions of children into orphans (WHO, 2015). UNAIDS (2014) indicates that the pandemic affects the most productive segments of the populations. Globally, an estimated 36.9 million people were living with HIV (PLWH) by the end of 2014 (WHO, 2015). Out of these, 2 million people were newly infected with HIV in 2014 (WHO, 2015). The sub Saharan African region remains most affected, with 25.8 million living with HIV and accounting for almost 70% of the global total of new HIV infections (WHO, 2015).

According to UNAIDS, (2013), there has been a dramatic change in the global HIV/AIDS landscape because of increased attention to care, treatment and support. At the end of 2014, it was estimated that 14.9 million people living with HIV had access to antiretroviral treatment globally, of which 13.5 million were receiving antiretroviral treatment (ART) in low- and middle-income countries (WHO, 2015). During the 2014 world AIDS conference, UNAIDS launched an initiative called the '90-90-90' initiative for 2020 with the prospective to end the pandemic by 2030 (UNAIDS, 2014). This means that 90% of all people living with HIV should know their HIV status, 90% of all people with diagnosed HIV infection should receive antiretroviral treatment and 90% of those on ART should be retained in care and virally suppressed.

Uganda has a population of 30.3 million people (Uganda Beaural of Statistics [UBOS], 2013) and it is one of the Sub Saharan African countries worst hit by HIV and AIDS epidemic (UNAIDS, 2014). In Uganda, the HIV prevalence is estimated to be 13.1% (UBOS, 2013). At the end of 2014, 4.2 million people were living with HIV, of which a million were adults aged 15-49 years and 2.3 women. HIV is the leading cause of death for all ages in Uganda. During the

2014 period, about 100,000 people died due to HIV/AIDS; The epidemic is estimated to have left at least 380,000 children orphaned (UNAIDS, 2014).

According to the global HIV/AIDS response epidemic update of 2011, more than 50% of the people eligible for treatment globally do not have access to antiretroviral therapy globally (UNAIDS, 2012). Fortunately, more and more countries are developing aggressive scale up plans with emphasis on early initiation and effective treatment. The national department of health in Uganda has responded to the HIV epidemic by developing policies and treatment guidelines for both HIV testing and treatment. The current ART treatment guidelines support individuals with HIV disease to be initiated on ART early when the CD4 count levels are below 500 cells per cubic millimeter. Special populations, such as pregnant women, discordant couples (one partner positive and the other negative) and patients with active tuberculosis are to be initiated on ART immediately after they are diagnosed with HIV regardless of CD4 count (Ministry of Health [MoH], 2014).

Due to this rapid scale up, the number of people accessing antiretroviral therapy in low- and middle-income countries has increased whilst HIV-related deaths have decreased. Uganda has also scaled up treatment rapidly with 671,066 adults and children initiated on ART at the end of 2014 (Ministry of Health [MoH], 2015). The number of health facilities initiating patients on ART has increased from 564 in 2012 to 592 in 2014. The increase was higher than the anticipated 500 facilities for 2015, and has made antiretroviral drugs (ARVs) more accessible to PLWH (MoH, 2015).

Despite the proven and documented benefits of ART (WHO, 2015), retention of patients in most antiretroviral treatment programs continues to be one of the biggest challenges. A number of people living with HIV are lost at different times in the continuum of care. Many studies have shown that the proportions of patients that remain in care following ART initiation are low and retention in care remains a challenge in many countries with a high burden of HIV/AIDS (Bucciardini et al., 2015). A review of 33 patient cohorts taking ART in 13 African countries suggested only 60% of patients remain in ART programs after two years with lost to follow up accounting for 56% of all attrition (Fox & Rosen, 2010).

## **1.2 Problem Statement**

The introduction of ART and its scale up has led to the improvement of quality of life of people living with HIV and AIDS in Uganda. However, patients who are initiated on ART do not adhere to treatment or remain in care. Evidence shows that more than 50% of patients discontinue treatment through death or lost to follow up (Scott et al., 2014). The service statistics for the Bushenyi district (2012 – 2015) indicate that only 45% of ART patients are retained in care at 36 months after initiating treatment (MoH, 2016).

Retention in care is one of the critical issues that need to be addressed in Uganda if the goal of ending the AIDS pandemic by 2030 is to be realized. Although research has been conducted on patients in ART programs in Uganda, most studies have focused on facility based adherence monitoring and factors associated with poor adherence to ART. Retention of patients in care, though recognized as a prerequisite for achieving any level of adherence, has received less attention. Retention in care of patients on ART program is of public health importance. Therefore, a better understanding of the factors affecting retention in care of patients on ART program in Uganda is needed to improve the quality of life of people living with HIV and AIDS in Uganda and reduce deaths due to HIV. It was therefore against this background that the researcher sought to conduct a study on factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District using KIU-TH as the case study.

## **1.3 Purpose of the study**

The purpose of this study was to assess the factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District using KIU-TH as the case study

## **1.4 Objective of the study**

- i. To find out the economic factors affecting retention in care of patients on antiretroviral treatment in KIU-TH
- ii. To assess the social factors affecting retention in care of patients on antiretroviral treatment in KIU-TH
- iii. To examine the health system factors affecting retention in care of patients on antiretroviral treatment in KIU-TH

## **1.5 Research questions**

- i. What are the economic factors affecting retention in care of patients on antiretroviral treatment in KIU-TH?
- ii. What are the social factors affecting retention in care of patients on antiretroviral treatment in KIU-TH?
- iii. What are the health systems factors affecting retention in care of patients on antiretroviral treatment in KIU-TH?

## **1.6 Significance of the study**

The study provides information that could be used for surveillance and targeting programs that would focus more on populations at risk particularly lost to follow up and missed clients. It will also assess factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District. The study also might make important contribution to future research by contributing to the existing literature particularly on contraceptive use among women of reproductive age. The study further avails information that could be used in policy planning and implementation particularly in vulnerable groups.

## **1.6 Study scope**

### **1.6.1 Geographical scope**

The study was conducted from KIU TH in HIV clinic. The KIU-TH is located in Bushenyi district, Ishaka division; just 10 meters along Kasese- Mbarara High way and 3 kilometers from Bushenyi District Head quarters. This place was chosen purposely because it has a significant number of HIV clients Bushenyi district.

### **1.6.2 Content scope**

The study assessed the factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District.

### **1.6.3 Time scope**

The research was carried out in a period of four months i.e. from December 2018 to March 2019.

### 1.7. Conceptual frame work

Schematic Model showing the Interrelationship between factors and the retention in care of patients on antiretroviral treatment

**Independent variable (IV)**

**Factors**

- Social factors
- Economic Factors
- Health system factors

**Dependent Variable (DV)**

**the retention in care of patients on ART**

- Lost to follow up
- Missed
- Attrition

Source: *Developed by the researcher basing on Andersen's behavioral model (2006)*

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.0 Introduction**

This Chapter presents a review of existing literature from previous studies conducted on health seeking behavior. The aim of this review is to avail different findings on the objectives of the researcher's current study.

#### **2.1 The economic factors affecting retention in care of patients on antiretroviral treatment**

Although the governments of most African countries are making efforts towards scaling up ART programs to benefit people living with HIV, factors such as cost of drugs leading to stock outs are contributing to low retention rates in ART programs. Supply chain management problems leading to frequent stock outs of ARVs are hindering access to ART services (WHO, 2015). With the number of patients being initiated on treatment rapidly growing and a median price for first-line treatment of US\$143 per person per year in low-income countries, many health systems are finding it difficult to ensure that there are adequate drugs and other supplies (WHO, 2013). These countries are often undermined by weak procurement and supply management systems, resulting in frequent shortages of ARVs and other essential commodities. Evidence shows that 34% of 91 low- and middle-income countries have experienced at least one stock out of a required ARV drug (WHO, 2013).

The presence of widespread poverty and food insecurity at household level may affect long-term retention of patients on ART treatment (Weiser et al., 2010). Taking ART in circumstances of high food insecurity and lack of finances may also increase the chances for absence from the clinical appointments and may compromise retention in care (Boyles et al., 2011). This is because some patients are forced to choose between paying transportation to attend the ART clinic and using the money for food (Tuller et al., 2010). This has implications for not only the day-to-day adherence but also increases the chances of loss to follow up.

Lack of formal education and poor health literacy about ART and HIV/AIDS can make patients not to understand about the effectiveness of medications. This may lead to challenges in adhering to treatment and poor retention in care (Tuller et al., 2010). At the initiation of ART, patients receive the most intensive counseling. However, once they are on treatment, counseling becomes

less intensive unless there is a problem. Adherence counseling should be provided whenever patients visit the clinic for medication refills or any clinical appointments because this is the time when any other health problems can be identified (Reda & Biadgilign, 2012). However, if good retention rates in ART programs are to be attained, information, education, and counseling need to be emphasized.

## **2.2 The social factors affecting retention in care of patients on antiretroviral treatment**

Social factors that influence retention in care include poor social support, relationships with marital partners, family members, or peers including stigma. These in turn affect individual behavior and actions (Roura et al., 2009). People living with HIV avoid disclosing their HIV status to their spouses, social network or other family members for fear of marriage breakdown, rejection, discrimination and loss of employment. When social support is threatened by involuntary disclosure of HIV status, individuals abandon treatment as a protective mechanism (Musheke et al., 2012).

Perceived quality of life, side effects of the drugs interpretation of illness and wellness after registering some improvements; ART can cause side effects just like any other drugs. Most patients who take ART, experience some side effects at one point. Some people may experience them and some may not. Van Dyk (2011) agree that most drugs that are used to manage HIV will have side effects ranging from mild to serious. According to Roural et al. (2009) these side effects in turn may affect patient seeking behavior and actions and may lead to attrition from ART care. Patients feel that side effects are inimical to their health and comfort and interfere with their engagement in livelihood activities (Musheke et al., 2012).

Patient interpretation of wellness can lead to lack of self-efficacy resulting in patient attrition from ART care. Mugisha et al. (2009) reported a poor sense of self-efficacy among patients receiving ART treatment to have led to discontinuation of treatment. Musheke et al. (2012) argue that a sense of wellbeing in patients receiving antiretroviral treatment decreases motivation to continue on treatment. There is need for intensive counseling at each follow up visit in order to improve retention in care.

HIV and AIDS related stigma is a serious obstacle to long term retention. It can be at individual, household and community levels and it is characterized by rejection, denial and social distance



(Musheke et al., 2012). Many people still associate HIV/AIDS with moral decadence and promiscuity, ultimately passing moral judgment on those infected. As a result, people living with HIV may face resentment, isolation and ridicule. Roura et al. (2009) argue that such attitudes and behavior do not only infringe on the rights of people living with HIV to respect and dignity but they also act as a strong disincentive for them to make use of any existing services for fear of being given names. This eventually leads to discontinuation of ART. A study from Malawi shows that stigma leads to non-retention in up to 25% of patients on ART (McGuire et al., 2010). If universal access to treatment is to be achieved, effective strategies addressing stigma and discrimination must be developed. Stronger community involvement in the process of stigma analysis and development of responses is recommended.

### **2.3 The health system factors affecting retention in care of patients on antiretroviral treatment**

Structural barriers to retention in care may include poor access to health facilities due to long distance to the health facility. A study in Uganda reports that long distances to ART centers were considered serious obstacles to care and led to poor retention of patients on ART program (Tuller et al., 2010). Making ART available at more sites that are convenient could address some of the challenges related to loss to follow-up. Studies have suggested that retention on ART care is better at primary healthcare sites within the heavily affected communities than at large centralized hospitals (Tuller et al., 2010). According to Boyles et al. (2011), making ART available at most local clinics in the community would make ART more accessible to patients.

Shortage of health personnel at the facility is among the drivers of poor retention of patients in care. Many public facilities in sub-Saharan Africa scaled up ART without a comparable increase in personnel to accommodate the larger number of patients (Lambdin et al., 2011). The shortage of human resource for health has severely hampered the rollout of ART in Sub-Saharan Africa (Callaghan, Ford and Schneider, 2010). According to Callaghan, Ford and Schneider (2010), task shifting should be considered for careful implementation if we are to offer high-quality, cost-effective care and retain more patients in care.

Shortage of health personnel places considerable pressure on the scarce medical workforce (Decroo et al., 2013). This may result in long waiting times for patients at the facility. As a

result, patients may be frustrated and discouraged from seeking care, leading to poor retention in care of the patients (Callaghan, Ford & Schneider, 2010).

High patient loads at health facilities also lead to long waiting times which is among the key drivers of attrition for patients on ART. According to Alamo et al., (2013), high patient load at health facilities may also result in long clinic appointments, long waiting times often lasting almost the whole day, poor staff attitudes and decreased quality of patient-provider interaction as well as overall patient dissatisfaction in their HIV care. These can lead to frustrations with most patients not returning to the clinic especially patients in employment.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.0 Introduction**

This chapter includes the various methods used for collecting and analyzing data for the research work. It also includes study design, study population, sample size determination, sampling, procedure, research instruments, data collection and analysis and ethical consideration.

#### **3.1 Study design**

The researcher used a cross-sectional research design to assess the factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District. This study design assisted the researcher to collect data at a single point in time.

#### **3.2 Study population**

The study targeted HIV infected clients on ART in the HIV clinic at KIU-TH. The researchers collected data for three consecutive clinic days i.e. Monday, Tuesday and Wednesday; and on average 150 clients attend the ART clinic on these days (Appointment registers on KIU-TH, 2019). The study also included the 7 health workers in the ART clinic of KIU-TH as Key informants.

#### **3.4 Selection criteria**

##### **3.2.1 Inclusion criteria**

All HIV positive clients attending ART clinic at KIU TH who were willing and consented to take part in the study.

##### **3.2.2 Exclusion criteria**

Anyone who was legible to participate in the study but failed to consent

#### **3.3. Sample size determination**

Sample size determination was calculated using the Slovene's formula for sample determination:

$$n = N / [1 + N (e)^2]$$

Where:

N= total number of respondents

e= level of precision (0.05)

n= sample size

The sample size was calculated using the Slovene's formula as shown below:

$$n=157/(1+157(0.05)^2)$$

$$n=157/1.3925$$

$$n=112$$

In this context, the researcher studied 112 respondents.

The sample will be taken as shown in the table below;

Category	Population	Sample size
Clients	150	5
Health workers	7	107
<b>Total</b>	<b>157</b>	<b>112</b>

### 3.4 Sampling Techniques

The researcher used simple random sampling technique to avoid bias; Simple random sampling technique was used to choose clients in order to obtain a sample size of 107 participants. In this, all the all the participants had equal chance of being part of the study sample. Purposive sampling was also used to select health workers.

### 3.5 Data collection method

Data was collected from clients attending ART clinic at Kampala International University teaching hospital. The researcher requested assistance from three students from Kampala International University after training them to help him in collecting data during their clinical practice.

### 3.6 Data collection tools

The researcher used questionnaires to collect data from the clients and interview guides to collect data from the health workers. The researcher also used a checklist to collect data on retention of the clients on ART care in KIU-TH

### 3.7. Quality control

This was done in the field immediately after administering to tools to ensure all questions are complete and ensure accuracy in recording the responses of the

respondents. This was done by listing down answers, reading through and ensuring that answers given are correctly written against each question.

### **3.8 Data Analysis**

After coding, Data was also analyzed using Excel and SPSS version 16.0. Bivariate analysis was performed using chi-square and p-value to aid the discussion of the findings and generating conclusions..

### **3.9 Ethical issues**

**3.9.1 Consent:** The researcher explained the essence of the study to the participants so as to create a rapport and trust from them; those who were willing to participate in the study signed the consent form.

**3.9.2 Confidentiality:** The responses from the respondents were shared among other participants not included in a study. This ensured confidentiality of their opinions.

**3.9.3 Respect for respondents:** All respondents were treated equally with utmost respect. No respondent was discriminated and victimized using the information obtained.

### **3.10 Limitations of the study**

The Researcher encountered limitations like; limited resources mostly on funding, some may fail to consent and others may conceal the information.

## CHAPTER FOUR

### DATA PRESENTATION, ANALYSIS AND INTERPRETATION

#### 4.0 Introduction

The researcher presented his findings and interpretation to guide him in conclusion and recommendations. The data was presenter in relation to the study objectives and questions.

#### 4.1 Background Information

**Table 4.1: the table showing the descriptive statistics of the demographic information**

Characteristic	Frequency	Percentage
<b>Sex</b>		
Female	67	59.4%
Male	45	40.6%
<b>Age group</b>		
Less than 20 years	8	7%
20-30 years	24	21%
31-40 years	32	29%
Above 40 years	48	43%
<b>Marital status</b>		
Single	12	11%
Married	48	43%
Separated	28	25%
Widow/er	24	21%
<b>Level of education</b>		
None	37	33%
Certificate	29	26%
Diploma	16	14%
Bachelor	24	21%
Post-graduate	7	6%
<b>Employment status</b>		
Unemployed	61	54%
Employed	51	46%

**Source: Primary data 2018**

In this study;

Most of the study respondents were female (59.4%); implying that more women came for treatment than men. 40.6% of the respondents were men.

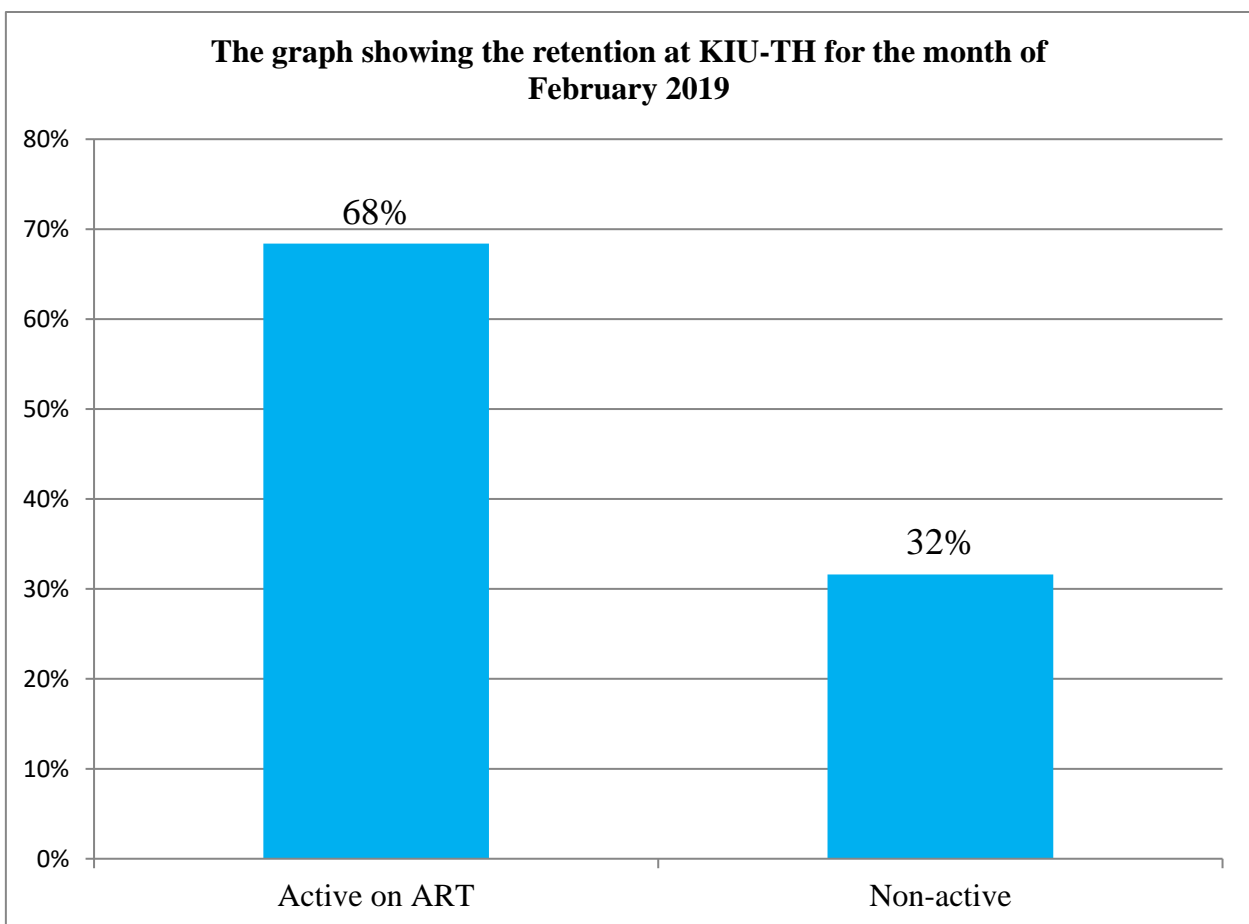
For age categories, 43% of the respondents were above 40 years of age; 29% were in the age group of 31-40years; 21% were in the age group of 20-30 years and 7% were below 20 years.

For marital status, 11% of the study respondents were single; 43% were married; 21% were widow/ers and finally 25% had separated.

On the level of education, 26% were of certificate level; 14% were of Diploma; 21% were of bachelors' level; 6% were of post graduate level and 33% had no education qualification.

On the employment status, 54% of the respondents were unemployed; 46% were employed.

#### **4.2 Retention of patients on antiretroviral treatment in at KIU-TH**



**Source: Secondary data 2018**

The retention of Patients on ART in the KIU-TH HIV clinic is 68% for the month of February 2019

#### 4.3 The economic factors affecting retention in care of patients on antiretroviral treatment in at KIU-TH

Economic Factors	Response	Frequency	Percentage	Chi-square	P-Value
Lack of transport	Strongly Agree	91	81%	9.585	0.005*
	Agree	21	19%		
	Neutral	0	0%		
	Disagree	0	0%		
	Strongly disagree	0	0%		
Lack of formal education	Strongly Agree	2	2%	5.141	0.097
	Agree	16	14%		
	Neutral	11	10%		
	Disagree	21	19%		
	Strongly disagree	62	55%		
Unemployment	Strongly Agree	59	53%		
	Agree	41	37%	6.484	0.010*
	Neutral	0	0%		
	Disagree	10	9%		
	Strongly disagree	2	2%		
Poverty	Strongly Agree	52	46%	9.321	0.001*
	Agree	60	54%		
	Neutral	0	0%		
	Disagree	0	0%		
	Strongly disagree	0	0%		
Long distance to the health facility	Strongly Agree	41	37%	7.613	0.032*
	Agree	65	58%		
	Neutral	3	3%		
	Disagree	2	2%		
	Strongly disagree	1	1%		
Mobility of employment	Strongly Agree	21	19%	9.615	0.000*
	Agree	32	29%		
	Neutral	3	3%		
	Disagree	25	22%		
	Strongly disagree	31	28%		

**P-value<0.05\* is considered statistically significant**



Most of the respondents (81%) of the respondents strongly agreed that lack of transport was the affecting retention, 19% agreed to the response and none of the respondents was neutral, disagreed or strongly disagreed.  $P\text{-value}=0.005<0.05$  showed that lack of transport had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

The findings in the table above show that 2% of the respondents strongly agreed that lack of formal education was the affecting retention, 14% agreed to the response and 10% were neutral, 19% disagreed and 55%strongly disagreed.  $P\text{-value}=0.097>0.05$  showed that 1 lack of formal education had no significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

The findings in the table above show that 53% of the respondents strongly agreed that lack of transport was the affecting retention, 37% agreed to the response and none of the respondents was neutral, 9% disagreed and 2% strongly disagreed.  $P\text{-value}=0.010<0.05$  showed that unemployment had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

Most of the respondents (54%) agreed to the response that poverty was the affecting retention or clients in care, 46% strongly agreed to the response and none of the respondents was neutral, disagreed or strongly disagreed.  $P\text{-value}=0.000<0.05$  showed that poverty had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

37% of the respondents strongly agreed that long distances to the health facility was the affecting retention of clients in care, 37% agreed to the response and 3% of the respondents was neutral, 2% disagreed and 1% strongly disagreed.  $P\text{-value}=0.032<0.05$  showed that long distances had had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

Most of the respondents (29%) agreed to the response that mobility of employment was the affecting retention or clients in care, 19% strongly agreed to the response and 3% of the respondents were neutral, 22% disagreed and 28% strongly disagreed.  $P\text{-value}=0.000<0.05$  showed that mobility of employment had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

### **Finding from the key informants;-**

Key informant 1 responded that “Patients coming from very far places may take them at least two to three hours to reach the clinic. Sometimes they do not come to collect their drugs due to lack of transport money”

Key Informant 2 responded that “neonatal septicemia was as a result of maternal risk factors such as fever and prolonged rupture of membrane”

### **4.4 The social factors affecting retention in care of patients on antiretroviral treatment in at KIU-TH**

<b>Social Factors</b>	<b>Response</b>	<b>Frequency</b>	<b>Percentage</b>	<b>Chi-square</b>	<b>P-Value</b>
Non-disclosure of HIV status	Strongly Agree	47	42%	9.585	0.000*
	Agree	21	19%		
	Neutral	6	5%		
	Disagree	23	21%		
	Strongly disagree	12	11%		
Excessive drinking of patients	Strongly Agree	62	55%	5.141	0.017*
	Agree	16	14%		
	Neutral	11	10%		
	Disagree	21	19%		
	Strongly disagree	2	2%		
Fear of marriage breakdown	Strongly Agree	59	53%	6.484	0.010*
	Agree	41	37%		
	Neutral	0	0%		
	Disagree	10	9%		
	Strongly disagree	2	2%		
Fear of discrimination from the society	Strongly Agree	23	22%	9.321	0.001*
	Agree	76	74%		
	Neutral	5	0%		
	Disagree	0	0%		
	Strongly disagree	0	0%		
HIV-related Stigma	Strongly	47	42%	7.613	0.022*

	Agree				
	Agree	65	58%		
	Neutral	0	0%		
	Disagree	0	0%		
	Strongly disagree	0	0%		
Fear of side effects of the drugs interpretation of illness	Strongly Agree	10	9%	3.615	0.721
	Agree	22	19%		
	Neutral	3	2%		
	Disagree	25	22%		
	Strongly disagree	50	48%		

**P-value<0.05\* is considered statistically significant**

Study findings in the table above indicate that:-

Most of the respondents (42%) of the respondents strongly agreed that non-disclosure of HIV-status to relatives was the affecting retention, 19% agreed to the response and 5% of the respondents were neutral, 21% disagreed and 11% strongly disagreed. P-value=0.000<0.05 showed that that non-disclosure of HIV- status to relatives had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

The findings in the table above show that 55% of the respondents strongly agreed that excessive drinking of alcohol by some clients was the affecting retention, 14% agreed to the response and 10% were neutral, 19% disagreed and 55%strongly disagreed. P-value=0.017>0.05 showed that excessive drinking of alcohol by some clients had no significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

The findings in the table above show that 60% of the respondents strongly agreed that fear of marriage breakdown was the affecting retention, 30% agreed to the response and none of the respondents was neutral, 9% disagreed and 2% strongly disagreed. P-value=0.010<0.05 showed that fear of marriage breakdown had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

Most of the respondents (74%) agreed to the response that fear of discrimination from the society was the affecting retention or clients in care, 22% strongly agreed to the response and 4% of the

respondents were neutral, none of the respondents disagreed or strongly disagreed to the response.  $P\text{-value}=0.000<0.05$  showed that fear of discrimination from the society had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

Most of the respondents (58%) of the respondents agreed that Fear of side effects of the drugs interpretation of illness was the affecting retention of clients in care, 47% agreed to the response and none of the respondents was neutral, disagreed or strongly disagreed.  $P\text{-value}=0.022<0.05$  showed that HIV-related stigma had had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

Most of the respondents (48%) strongly agreed to the response that fear of side effects of the drugs interpretation of illness was the affecting retention of clients in care, 22% strongly agreed to the response and 2% of the respondents were neutral, 19% agreed and 9% strongly disagreed.  $P\text{-value}=0.0721>0.05$  showed that fear of side effects of the drugs interpretation of illness had no significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

#### **4.5 The health system factors affecting retention in care of patients on antiretroviral treatment in at KIU-TH**

<b>Health Factors</b>	<b>Response</b>	<b>Frequency</b>	<b>Percentage</b>	<b>Chi-square</b>	<b>P-Value</b>
Poor health literacy	Strongly Agree	59	53%	6.484	0.042*
	Agree	41	37%		
	Neutral	0	0%		
	Disagree	10	9%		
	Strongly disagree	2	2%		
Shortage of health personnel at the facility	Strongly Agree	21	19%	9.615	0.049*
	Agree	32	29%		
	Neutral	3	3%		
	Disagree	25	22%		
	Strongly disagree	31	28%		
Long waiting hours for patients at the facility	Strongly Agree	101	91%	9.585	0.000*
	Agree	11	9%		
	Neutral	0	0%		
	Disagree	0	0%		
	Strongly disagree	0	0%		

Poor staff attitudes	Strongly Agree	52	46%	9.321	0.000*
	Agree	60	54%		
	Neutral	0	0%		
	Disagree	0	0%		
	Strongly disagree	0	0%		
Decreased quality of patient-provider interaction	Strongly Agree	41	37%	7.613	0.021*
	Agree	65	58%		
	Neutral	3	3%		
	Disagree	2	2%		
	Strongly disagree	1	1%		

**P-value<0.05\* is considered statistically significant**

Study findings in the table above indicate that:-

Most of the respondents (53%) of the respondents strongly agreed that Poor health literacy was the affecting retention, 37% agreed to the response and none of the respondents was neutral, 9% disagreed and 2% strongly disagreed. P-value=0.042<0.05 showed that Poor health literacy had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

The table above shows that 19% of the respondents strongly agreed that Shortage of health personnel at the facility was the affecting retention, 29% agreed to the response and 2% were neutral, 22% disagreed and 28%strongly disagreed. P-value=0.049<0.05 showed that shortage of health personnel at the facility had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

The findings in the table above show that 91% of the respondents strongly agreed those long waiting hours for patients at the facility were the affecting retention, 9% agreed to the response and none of the respondents was neutral disagreed or strongly disagreed. P-value=0.000<0.05 showed that long waiting hours for patients at the facility had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

Most of the respondents (54%) agreed to the response that poor staff attitudes was the affecting retention or clients in care, 46% strongly agreed to the response and none of the respondents was neutral, disagreed or strongly disagreed. P-value=0.000<0.05 showed that poor staff attitudes had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

37% of the respondents strongly agreed that long distances to the health facility was the affecting retention of clients in care, 37% agreed to the response and 3% of the respondents was neutral, 2% disagreed and 1% strongly disagreed.  $P\text{-value}=0.032<0.05$  showed that long distances had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

Finally, most of the respondents (58%) agreed to the response that there was decreased quality of patient-provider interaction which was the affecting retention or clients in care, 37% strongly agreed to the response and 2% of the respondents were neutral, 2% disagreed and 1% strongly disagreed.  $P\text{-value}=0.021<0.05$  showed that decreased quality of patient-provider interaction had a significant effect on the retention in care of patients on antiretroviral treatment in KIU-TH.

## **CHAPTER FIVE**

### **DISCUSSION OF THE FINDINGS, CONCLUSIONS AND RECOMMENDATIONS**

#### **5.0 Introduction**

This chapter presents the discussion of the findings with respect to the study objectives, conclusions and recommendations of the study.

#### **5.1 Discussion of the study findings**

On economic factors; the study found out that poverty, long distances, lack of transport, loss of employment and employment mobility had a significant effect on the retention of patients on antiretroviral treatment in care at KIU-TH. This was in agreement with Boyles (2011) who found out that taking ART in circumstances of poverty and unemployment increase the chances for absence from the clinical appointments and may compromise retention in care. Tuller (2010) added that some patients get lost or miss appointments because of the long distances from the ART centre.

On social factors; the study found out that excessive drinking of alcohol; fear of marriage breakdown, non-disclosure of HIV status, stigma, and fear of discrimination from the society had a significant effect on the retention of patients on antiretroviral treatment in care at KIU-TH. This was in line with Roural et al. (2009) who revealed that these side effects in turn may affect patient seeking behavior and actions and may lead to attrition from ART care. Musheke (2012) added that people living with HIV avoid disclosing their HIV status to their spouses, social network or other family members for fear of marriage breakdown, rejection, discrimination and loss of employment which compromise retention in care.

On health system factors; the study found out that poor health literacy, decreased quality of patient-provider interaction, poor health staff attitudes and long waiting hours for patients at the facility had a significant effect on the retention of patients on antiretroviral treatment in care at KIU-TH. These findings were in agreement Callaghan, Ford & Schneider (2010) who revealed that long waiting times for patients at the facility frustrated and discouraged from seeking care, leading to poor retention in care of the patients. Alamo (2013) added that high patient load at health facilities may also result in long clinic appointments, long waiting times often lasting almost the whole day, poor staff attitudes and decreased quality of patient-provider interaction as well as overall patient dissatisfaction in their HIV care.

## **5.2 Conclusion**

The study results indicated that the retention of KIU-TH HIV clinic was 68% in February 2019; the factors that affected patient retention in care were particularly long distance to ART center, cost of transportation and high patient load with long waiting times at the clinic represented the greatest barrier to accessing treatment, excessive drinking of some patients, HIV related- stigma and non-disclosure of HIV status to sexual partners and families are significant barriers and shortage of health personnel. However, if the needs of patients are to be met, systems in health facilities need to be strengthened to reduce loss to follow up, increase adherence and promote long term retention.

## **5.3 Recommendation**

From the study findings, the study revealed that patients who are started on ART treatment come to discontinue treatment due cost of transportation to ART centers. With regard to lack of money for transportation, the researcher recommended that patients need to be continually encouraged to take treatment at their nearest treatment center.

Stigma and non-disclosure of HIV status was perceived to be a hindrance to achieving good adherence and retention in care of patients on ART program. The researcher therefore suggested that health care providers including adherence support workers should take an active role in the fight against stigma. Strategies that can encourage patients to improve on disclosure of HIV status should be developed.

Indeed, many HIV positive persons were reported to have resorted to heavy alcohol consumption and this alcoholism impact negatively on their adherence and retention in care in the long run. Therefore, heavy drinking should be discouraged by substance abuse counselors because it can make them non-suppressing.

Another impediment to patient retention was long waiting hours and high patient loads at ART clinic. The researcher recommended that different appointments should be given to the patients to minimize the health personals workloads.

## **5.4 Areas for further studies**

The researcher suggested that other researchers may do research on the following;



- i. The consequences of poor retention
- ii. Measures of improving retention among HIV clients
- iii. Retention in adolescents
- iv. Retention in pregnant and lactating mothers

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## **Appendix I: Consent Form**

I Listern Tenga Tenga, an Undergraduate student of Kampala International University western campus currently conducting my research with the following title: Factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District using KIU-TH as the case study.

You have therefore been chosen as a key person who support in answering this questionnaire if extremely important for the success of this study. I therefore kindly request for your written consent to participate in the afore mentioned study and I guarantee utmost confidentiality once you accept to participate in this study.

I ..... the undersigned, hereby provide informed consent to participate in this study. I am of sound mind, healthy and have not been coerced in any way to be a participant.

SIGNATURE: .....

DATE: .....

## Appendix II: Questionnaire

My name is **Listern Tenga Tenga**; I am conducting a research about “factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District”. The questionnaire items are about the study; and I kindly request you to participate in responding to the questions below accordingly to help me getting the information needed in my research. The information given will be treated as confidential and the results of the study will be used for academic research purposes only.

### PART A: Bio-data

Tick the correct response:

#### 1. Sex

Male ☐ Female ☐

#### 2. Age group

Less than 20 ☐  
20-30 ☐  
31-40 ☐  
Above 40 ☐ ☐

#### 3. Marital Status

Single ☐  
Married ☐  
Divorced / Separated ☐  
Widowed ☐

#### 4. Employment status

Employed ☐  
Unemployed ☐

#### 5. Level of education

None ☐  
Certificate ☐  
Diploma ☐  
Bachelor degree ☐  
Post graduate ☐

**Part B: the economic factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District**

**Key: 5- Strongly agree, 4-Agree, 3 Neutral, 2- Disagree, 1-Strongly disagree**

Characteristic	5	4	3	2	1
Lack of transport					
Lack of formal education					
Unemployment					
Poverty					
Long distance to the health facility					
Loss of employment					
Employment mobility					

**Part C: the social factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District**

**Key: 5- Strongly agree, 4-Agree, 3 Neutral, 2- Disagree, 1-Strongly disagree**

Characteristic	5	4	3	2	1
Non-disclosure of HIV status					
Excessive drinking of patients					
fear of marriage breakdown					
Fear of discrimination					
Stigma.					
Fear of side effects of the drugs interpretation of illness					

**Part D: the health system factors affecting retention in care of patients on antiretroviral treatment in Bushenyi District**

**Key: 5- Strongly agree, 4-Agree, 3 Neutral, 2- Disagree, 1-Strongly disagree**

Characteristic	5	4	3	2	1
Poor health literacy					
Shortage of health personnel at the facility					
long waiting hours for patients at the facility					
poor staff attitudes					
decreased quality of patient-provider interaction					

**Thank you for your time**

### **Appendix III: Interview guide**

1. Name ..... (Optional)
2. Position held in the clinic
3. On average clients do you enroll in care in a month?
4. When are your appointment days in the clinic?
5. Do all clients attend on their appointments?
6. What reasons do they give for not attending?
7. Do you know about retention? What is it?
8. What are the reasons for poor retention among your clients? Categorize them into Social, Economic, and health system reasons to the interviewee
9. How can retention be improved in your clinic?

**Thank you for your time**

**Appendix IV: A Gantt chart showing a work plan of activities for the research work**

S/N	Planned Activities	Dec 2018	Jan 2019	Feb 2019	Mar 2019
1	Development of concepts and ideas through consultations and discussions				
2	Selection of research topics and their approval				
3	Writing of proposals and their submissions				
4	Data collection				
5	Submission of drafts				
6	Submission of final dissertation				



**Appendix V: Estimated Budget**

<b>Item</b>	<b>Estimated Cost (Ugshs)</b>
Internet	30,000=
Stationary	80,000=
Printing Phase I (Proposals)	30,000=
Data collection	150,000=
Printing Phase II (Reports)	60,000=
Binding	35,000=
Transport	100,000=
Airtime	20,000=
Consultation	50,000=
Miscellaneous	50,000=
<b>Total</b>	<b>605,000=</b>

ListernTengatenga (BMS/0051/141/DF)

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Box 71

Bushenyi

09<sup>TH</sup> March, 2019

The Dean

Faculty of Medicine and Dentistry

Kampala International University

Box 71

Bushenyi

Dear Sir/Madam,

APPROVAL LETTER FOR DATA COLLECTION

I would like to apply for the authorization letter in order to collect data on the research topic: 'The factors affecting retention in care of patients on antiretroviral treatment' which is to be done in KIU Teaching Hospital and my supervisor is Professor Kaem Shirali who has reviewed my proposal and made some corrections on it.

The study shall look at the economic, social and health system factors that affect the retention in care of patients on antiretroviral treatment in Kampala International University Teaching Hospital.

I will be glad if my application shall meet your favorable consideration.

Yours faithfully,



LISTERN TENGATENGA

*Approved  
Subscribed  
18.03.19*