

**SOCIO-ECONOMIC CONDITIONS AND RETENTION OF CLIENTS IN HIV CARE  
AND TREATMENT AT KAGADI HOSPITAL, UGANDA**

*BY*

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2014



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## DECLARATION

I, Silver Kasigeire, hereby declare that this research is entirely my original work and has never at any one time been submitted for any award at this or any other university/institution of higher learning.

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Signed.....

Silver Kasigeire

Date.....

## **DEDICATION**

This book is dedicated to my family: Wife Norah, Children: Arnold, Elivan and Eleanor, and my Parents.

## **ACKNOWLEDGEMENTS**

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## **List of abbreviations**

AIDS – Acquired Immune Deficiency Syndrome

ART – Anti-Retroviral Therapy

ARVs-Anti-Retroviral Drugs

CD4- Cluster of differentiation

CVI- Content Validity Index

HAART-Highly Active Antiretroviral Therapy

HC – Health Centre

HIV – Human Immunodeficiency Virus

HMIS-Health Management Information Systems

ICAP- International centre for AIDS care and treatment

IDI- Infectious Diseases Institute

IMB-Information, Motivation and Behaviour

PMTCT- Prevention of Mother to child transmission of HIV

PNFP- Private not for profit Health facilities

RLS- Resource limited settings

SPSS- Statistical package for social sciences

UMI-Uganda Management Institute

UNAIDS- United Nations Joint Programme on HIV/AIDS

## ABSTRACT

The purpose of the study was to investigate the effects of socio-economic factors on HIV patient retention under care and treatment in Kagadi Hospital. The study set out to examine the effect of transport to the hospital, the financial status of the patient and social support accorded to the patient on the retention of patients at the hospital. The study was both qualitative and quantitative in nature and it evaluated HIV-infected adults who were visiting the hospital since October 2011 as well as hospital management staff. The study identified a random sample of 221 patients under taking HIV care and 5 hospital management staff. The findings revealed that transport costs to the health facility were a burden to the patients seeking HIV care and that the distance they travelled to the health centre affected retention of patients ( $\rho = 0.210$ ,  $P = 0.02$ ). Similarly, the financial status of the patients affected their retention at Kagadi hospital ( $\rho = 0.243$ ,  $P = 0.000$ ). Social support offered to HIV patients also minimally improved the retention of HIV patients as compared to the absence thereof. ( $\rho = 0.214$ ,  $P = 0.001$ ). In conclusion, even in the case where drugs are supplied freely, transport to the hospital, lack of consistent incomes and the lack of social support were found to be barriers to retention at Kagadi hospital. Efforts to improve the above factors would increase HIV patient retention at the Hospital.

# CHAPTER ONE

## INTRODUCTION

### 1.0 Introduction

The fight against the AIDS pandemic is currently the world's most deadly war. In spite the recent improved access to antiretroviral therapy and care programs in many parts of the world, the AIDS epidemic claimed 1.8 million lives in 2010 and has cumulatively killed about 34 million people since it was first recognised in 1981 (UNAIDS, 2011). This study was an examination of the socio-economic conditions affecting retention of clients in HIV care and treatment at Kagadi Hospital an ART accredited centre, in Kibaale District. Socio-economic conditions (Transport, Financial status, Social support) were considered to be the independent variables while retention of clients in HIV care was the dependent variable. This chapter presents the back ground to the study, statement of the problem, general and specific objectives, research questions, hypotheses, conceptual frame work, scope, significance, justification, limitations and operational definitions of the terms used.

### 1.1 Background to the Study

#### 1.1.1 Historical Background

In the half decade since the first large-scale antiretroviral treatment (ART) programs for HIV/AIDS were launched in sub-Saharan Africa, much attention has focused on patients' day-to-day adherence to antiretroviral (ARV) medications (Gill *et al*, 2005). Long-term retention of patients in treatment programs, a prerequisite for achieving any adherence at all, has received far less attention.

Perhaps because most large scale treatment providers have few resources available to track missing patients, most studies treat patient attrition as a side issue and focus solely on describing those patients who are retained. Moreover, adherence can be assessed over very short periods, whereas long-term retention requires, by definition, long-standing programs.

ART programs in Africa are retaining, on average, roughly 80% of their patients after 6 months on ART and between one-fourth and three-fourths of their patients by the end of 2 years, depending on the estimating method used. Prior to the availability of ART in Africa, the median interval from HIV infection to AIDS-related deaths was under 10 years; once a patient was diagnosed with AIDS, median survival was less than 1 year (Morgan *et al*, 2002). Since most patients in Africa initiate ART only after an AIDS diagnosis, most ART patients would have died within a year had antiretroviral therapy not been available. Each patient who is retained in care and on ART can thus be regarded as a life saved and a source of tremendous benefit to patients' families and communities.

For those who have struggled to launch and expand treatment programs in resource-constrained settings, reaching a 60% patient retention—and thus survival—rate after two years of treatment, as estimated by the Kaplan-Meier survival analysis, in just a few years' time is an extraordinary accomplishment. It is also noteworthy in the global context: in developed countries, adherence to medication for chronic diseases in general averages only 50% (Sebate, 2003). Similarly, treatment completion rates for tuberculosis [for the case of HIV patients], which requires a temporary rather than permanent commitment to adherence and a less demanding dosing schedule, average 74% in the African region, with a range among countries from 22% to 94% (WHO, 2007).



Taken in the context of retention in general, the record of African ART programs lies within the bounds of previous experience.

## **1.1.2 Theoretical Background**

The study was guided and informed by Andersen's Socio-behaviour model so as to explain the relationships between socio-economic factors and patient retention under HIV care.

### **1.1.2.1 Andersen's Health Care Utilisation Model (The Socio-behavioural Model)**

Andersen's behavioral model (Andersen, 1968) was created to empirically test hypotheses about inequality of access to health services. It addresses the concern that some sectors of society - people who live in rural areas - receive less health care provision than the rest of the population (Andersen & Newman, 1973). Andersen's model views access to services as a result of decisions made by an individual, which are constrained by their position in society and the availability of health care services. This model, therefore, allows us to explore hypotheses regarding social inequalities. The model contains three sets of predictive factors: predisposing, enabling and need factors. It assumes that a sequence of factors determines the utilization of health services: the predisposition to use services, the ability to use services and the need to use services. Andersen's first study focused on the family as the unit of analysis, and hence several family-level variables were used. Later versions of the model focus on the individual as the unit of analysis (Andersen & Newman, 1973).

## **1.1.3 Conceptual Background**

Patient retention in HIV care is a modifiable risk factor that profoundly affects outcomes of HIV disease at the individual and population levels.

In published studies, patient retention is conceptualized and measured in 3 different ways: appointments missed, medical visits at regularly defined intervals, and a combination of those methods focusing on use of the health care system. Patient retention is most frequently studied as missed appointments, missed visit rates, and the percentage of patients who miss appointments over a defined period. (Israelski *et al*, 2001; Lucas, Chaisson & Moore, 1999; Catz *et al*, 1999).

Missed appointments are defined as those not cancelled or rescheduled; missed appointment rates are the proportion of total appointments that are missed and are also referred to as a missed visit proportion, which has been used with a threshold of 25% to compare association with independent variables (Mugavero, Lin, & Willig, 2009).

These 3 ways of measuring patient retention are useful in different ways. Generation of a list of patients who missed an appointment on a particular day is easy. Staff can then act quickly to re-engage patients in care. Because missed appointments cost both time and revenue (Moore, Witherspoon & Probst, 2001), minimizing them is a priority from a clinic perspective.

Measuring patient retention requires maintaining a case list and tracking whether patients on that list attend clinic during specific periods. In addition, a detrimental time lag may occur by the time a patient is identified as having fallen out of care or is no longer within the reach of the health care system. This approach allows for a more systematic look at the group of patients who are not retained, so that resources can be better targeted to engaging them.

However, retention of patients in antiretroviral therapy programs is dependent on a number of factors like lack of stable income and inadequate support from social networks among others.

This study specifically looked at the impact of the socio-economic factors on retention. Socioeconomic factors are the social and economic experiences and realities that help mould one's personality, attitudes, and lifestyle. This study conceptualised these factors in the following dimensions; transport to the service point, financial status, and clients' social support.

#### **1.1.4 Contextual Background**

Kibaale District is located approximately 200 kilometers northwest of Kampala, Uganda's largest city, on an all-weather tarmac highway linking Kampala to Mubende and the murrum road to Kibaale District. The district is served by 54 government and private not for profit (PNFP) health facilities with only 10 of them accredited to offer HIV/AIDS care and treatment services. These include; Kagadi Hospital, Kibaale H/C IV, Kakumiro H/C IV, Kakindo H/C IV, Kisiita H/C III, Nkooko H/C III, Nyamarwa H/C III and Kyaterekera H/C III.

Kagadi Hospital was established to provide health care services to the people in the town centre (now town council) and its outskirts. The Hospital began offering HIV/AIDS services including ART services in the year 2004. This was possible with support from The AIDS Support Organisation (TASO) which begun a mini-TASO ART clinic where clients receive HIV Counselling and Testing (HCT), nutritional support, treatment for opportunistic infections and ART. A number of other partners have since provided support for HIV/AIDS service delivery in this Hospital. These are; Baylor Uganda and Irish AID, and the Infectious Diseases Institute (IDI). The clinic has since grown with 5,773 clients in care by 31<sup>st</sup> December 2011.

A number of researches have been carried out on the factors that determine the retention rates of HIV patients. For example, Fisher, Fisher, & Harman (2003) concluded that motivation and behavioural skills were assumed to be the fundamental behavioural determinants of adherence to

HIV-care attendance and retention while Wringe *et al* (2009) revealed that long waiting hours, family pressures and costs of accessing services were affecting retention of clients in HIV care,

## **1.2 Problem Statement**

Retaining patients infected with Human Immuno deficiency Virus (HIV) in medical care is a major priority for both providers and public health organizations. Since the advent of highly active antiretroviral therapy (HAART) in 1996, health out comes have dramatically improved for persons living with HIV infections. Continuing improvement depends on connecting HIV infected patients with and maintaining them in on going care (Horstmann, Brown & Islam, 2010).Despite the documented benefits of retention of clients in HIV care, Smith, Jeffrey & Amico (2012) assert that retention rates at HIV care sites have not been impressive.

In initial work, the sampling-based approach found the Uganda national estimates of retention in care to be at 70%. (Geng, Glidden, Bwana et al, 2010). At Kagadi Hospital, records show that out of 784 clients who were enrolled into HIV care between October 2011 and June 2012, only 450 were reported to have been active by end of September 2012 (HMIS, 2012).This means that only 57.4% had been retained in care. This is low retention rate as compared to Uganda national estimate and estimates from other studies. A study in northern Uganda for example presented a 73.1% retention rate at the Kitgum district hospital while a 3-year prospective study conducted in a community based ART program in South Africa presented a retention rate of 90.3%

A number of studies have been undertaken on the factors that determine retention of HIV patients in Uganda (Nash *et al.*, 2010; Emenyonu *et al.*, 2010;Amuron *et al.*, 2009). They for example identified that a number of patients had no assurance of a daily meal, walked long

distances to seek care and those that were faced with stigmatization were unlikely to return for follow-up. They also found out that the health care providers that were overworked, poorly remunerated and poorly motivated were likely to provide a less than satisfactory quality of service. The above factors explain why retention has been difficult in the entire country; we also know that some parts of the country are not the same due to the different context. Even then, no such study has been carried out in Kagadi hospital. This called for a study in this area.

### **1.3 Purpose of the Study**

The purpose of the study was to investigate the effects of socio-economic conditions on retention of HIV patients under care and treatment at Kagadi Hospital.

### **1.4 Specific Objectives**

- i. To examine the effect of transport to the Hospital on a patient's retention as an HIV client in care and treatment at Kagadi Hospital.
- ii. To examine the effect of financial status on retention of HIV clients in care and treatment at Kagadi Hospital.
- iii. To examine the effect of HIV clients social support on their retention in care and treatment at Kagadi Hospital.

### **1.5 Research Questions**

- i. What is the effect of transport to the hospital on retention of HIV clients in care at Kagadi Hospital
- ii. What is the effect of the patient's financial status on their retention as an HIV client in care at Kagadi Hospital.

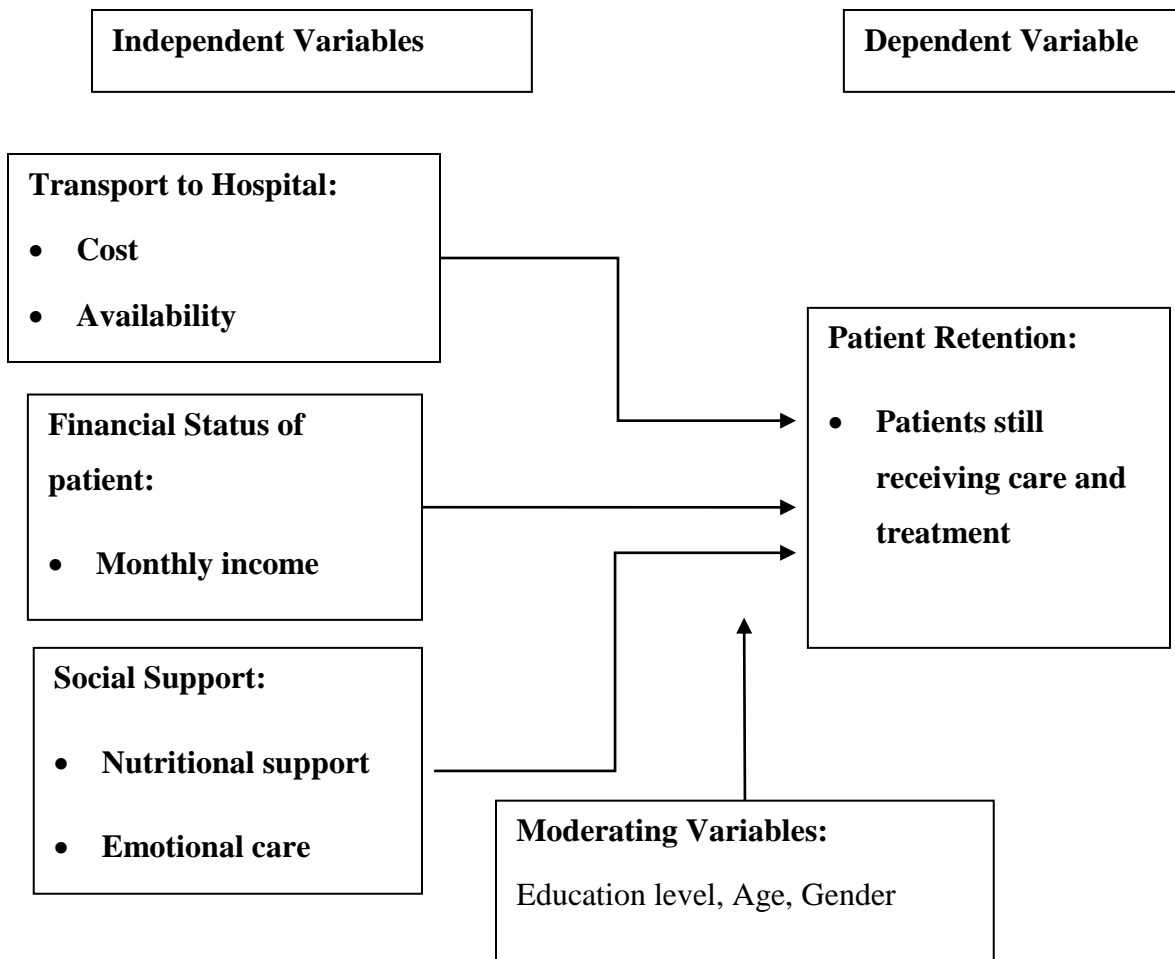
- iii. What is the effect of social support provided to the patient on their retention in HIV care at Kagadi Hospital.

## **1.6 Hypotheses**

- i. There is a significant relationship between transport to the hospital and retention of HIV clients in care and treatment.
- ii. Financial status of the patient affects their retention in HIV care and treatment
- iii. The social support accorded to the patient has an effect on their retention in HIV care?

## **1.7 Conceptual Framework**

A diagrammatic illustration of the cause-effect relationship between the independent variables, moderating variables and the dependent variable that were used in this research.



**Source:** Adapted and modified from Mugisha *et al* (2009)

The vast majority of the world’s 33 million HIV-infected patients—including the over 4 million on ART already reside in resource-limited settings (RLS) such as sub-Saharan Africa where retention in care potentially takes on an important role. Retention in care allows provision of medications for opportunistic infections, ongoing staging, prevention of mother-to child transmission (pMTCT), and prompt initiation of ART once indications arise

For patients who have tested HIV+ and are enrolled on care and treatment, poor retention prevents ongoing immunologic and clinical deterioration. This has been found to be a result of major determinants such as poor financial status of the patient, social support accorded to the patient and transport costs/means to the health unit among others. Therefore, interventions to improve retention in care should focus on implementation strategies to reduce the effect of these factors.

## **1.8 Scope of the study**

### **1.8.1 Geographical scope.**

The study was done in Kibaale District focusing on Kagadi Hospital. The Hospital is located in Kagadi town council, which is located 42 Km west of Kibaale District head quarters. Kibaale District is located in the mid western region of Uganda about 220 Km from Kampala city. The District borders with Hoima District in the North, Kyankwanzi in the North east, Mubende in the east, Kyegegwa in the south, Kyenjojo in the west and Lake Albert in the North West. Kibaale district is thus located in the Albertine region.

### **1.8.2 Content scope**

The study focused on retention of clients in HIV care as the dependent variable. Retention was measured by the HIV patients who are still obtaining ART.

The independent variables were socio-economic conditions, namely: transport, clients' financial status and social support. Transport had dimensions of costs involved by the patient in order to obtain HIV care and treatment services as well as means used for transport. On the other hand,



financial status was measured by the monthly income of the respondent while social support was measured in terms of emotional care and nutritional support.

### **1.8.3 Time scope**

The study focused on the retention level of clients who enrolled for HIV care from October 2011 to June 2012 at Kagadi Hospital.

## **1.9 Significance of the Study**

The study provides a clearer understanding of the specific causes of loss to follow up for clients as well as the socio-economic conditions that affect retention of HIV clients in HIV care in the district. The study results for example among others revealed that transport costs/long distances travelled were a big burden to clients. This information will be useful to the service providers, health facility In-charges, the District Health Teams and the HIV/AIDS service implementing partners in Kibaale District. The information will guide the development of more effective and evidence based strategies to improve retention of clients in care.

## **1.10 Justification of the Study**

HIV care/treatment has proved to be effective and yielded fruitful results for clients who adhere to the therapy. However, client retention in HIV care at Kagadi is quite low and there are many clients lost to follow up. Transport costs and means, financial challenges and social support are major barriers to patient retention in many developing countries including Uganda. The high rates of loss to follow-up due to these factors have significantly limited the effectiveness of ART and other preventative strategies in these countries.

There was an urgent need for information on retention rates in Kibaale and the magnitude of the problem caused by the highlighted factors in the area which would effectively guide the optimal delivery of health care services.

### **1.11 Definition of key terms**

**Attrition:** This is the discontinuation of ART including death, loss to follow-up, and stopping ARV medications while remaining in care.

**Loss-to-follow-up:** The phrase lost-to-follow-up is frequently used in medicine to describe patients who you can no longer locate despite your best efforts. This implies that it is either the patient's fault, or due to circumstances beyond one's control. In this case, it refers to patients receiving ART who were more than 3 months late for a scheduled clinic or pharmacy visit and who were neither transfers-out nor relocations.

**Transfers-out:** Patients whose care and ART treatment was transferred to another ART accredited health facility.

**Relocations:** Patients who moved to another location but who were not referred to an ART service in the new area.

**Non-death Losses:** The sum total of transfers-out, relocations and losses-to-follow up.

#### **Social Support:**

Social support is conceptualized as one of a number of antecedent stress resistance resources that contribute to positive adaptational outcomes. Having people in one's life during a stressful episode from whom one receives emotional, informational, and/or tangible support is a major factor mediating such outcomes.

**HIV Care:**

This is an essential component of any definition of clinical care and support. It includes access to early testing, access to formulations for ART and access to cotrimoxazole as a prophylaxis in HIV-exposed and infected persons. Treatment adherence information and support is especially important for persons living with HIV whose treatment is often either missed or given in inappropriate quantities. Care-providers can deliver ART in a formulated amount suitable at exact intervals.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter focuses on the review of various data related to the topic/area of study. In this chapter, study variables and their effect on retention of HIV positive clients in HIV care and treatment programmes were reviewed. The variables covered included; the independent variables-socio economic conditions namely; transport, financial status, and clients social support. The dependent variable was retention of clients in HIV care. The theory that guided the research was also included in this chapter.

#### **2.2 Theoretical Review**

Several comprehensive models of health behavior adoption and maintenance have been applied individually and as a systems-level approach to accessing HIV-care, including: Andersen's Behavioral model of Health Service Utilization (Andersen, 1995; Christopoulos, Das, & Colfax, 2011; Gelberg, Andersen, & Leake, 2000; Mkanta & Uphold, 2006; Moneyham et al., 2010; M. J. Mugavero, 2008; Ulett et al., 2009), the Chronic Care Disease Model (Gifford & Groessler, 2002; Health Resources and Services Administration, 2006; Wagner, 1998), the Health Belief Model (Mkanta & Uphold, 2006; Rosenstock, 1966), and the Socio-ecological Framework (McLeroy, Bibeau, Steckler, & Glanz, 1988; M. J. Mugavero et al., 2011).

However, models that provide both a good characterization of underlying determinants of retention in HIV care and lead to actionable intervention approaches are lacking. Therefore, a

theoretical frame work that provides an in-depth systematic understanding of the core facilitators and barriers to self sustained retention in HIV care is desperately needed to inform efforts supporting PLWH in maintaining routine HIV care with in the recommended intervals (Smith *et al.*, 2012). Andersen’s Socio-behavioural model was used to guide this study.

### 2.2.1 Andersen’s Health Care Utilisation Model

The Health care Utilisation or Andersen’s Socio-behavioural model (Andersen & Newman, 1975) groups in a logic sequence three clusters or categories of factors (predisposing, enabling and need factors) which can influence health behaviour. The model was specifically developed to investigate the use of biomedical health services. Latter versions have extended the model to include other health care sectors, i.e. traditional medicine and domestic treatments (Weller, Ruebush, & Klein, 1997). Figure 1 below outlines the different categories. An adaptation of the model has been proposed for studying health-seeking behaviour for diseases (Rauyajin, 1991).

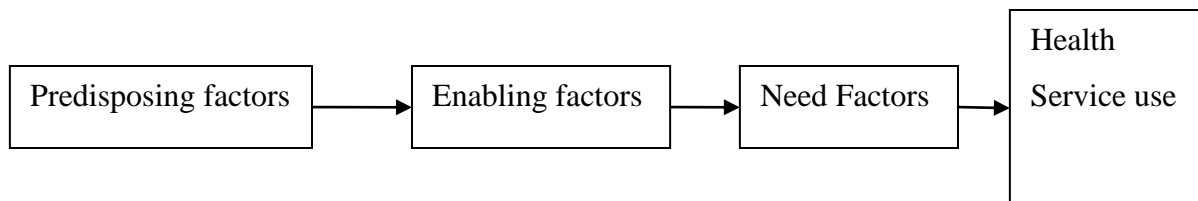


Figure 1: Health Care Utilization Model

Examples of the factors organized in the categories of the Health Care Utilization Model (mainly following Weller et al. 1997) are:

Predisposing factors: age, gender, religion, global health assessment, prior experiences with illness, formal education, general attitudes towards health services, knowledge about the illness etc.

Enabling factors: availability of services, financial resources to purchase services, health insurance, social network support etc.

Need factors: perception of severity, total number of sick days for a reported illness, total number of days in bed, days missed from work or school, help from outside for caring etc.

Treatment actions: home remedies (herbal, pharmaceuticals), pharmacy, over the counter drugs from shops, injectionists, traditional healers, private medical facilities, public health services etc.

The model centers specifically on treatment selection. It includes both material and structural factors, which are barely taken into account in the social psychology models. Weller and colleagues (1997) emphasized its particular use for working with statistical data on actual cases.

The model has also been used for gaining evidence on the weight of different factors for health service use. Based on the data of Demographic and Health Surveys, a comparative study of six African countries has been carried out, using the categories proposed by Andersen (Fosu, 1994).

Andersen's model has been modified in the International Collaborative Study on Health Care .

In addition to the predisposing factors and enabling factors, this version includes Health Service System factors, referring to the structure of the health care system and its link to a country's social and political macro-system. This is a valuable extension as it puts emphasis on the link of health-seeking behavior with structural levels within a macro-political and economic context. However, the model omits the 'need factors' which are central for understanding health-seeking behavior (Weller et al., 1997)

## **2.3 Socio-economic conditions and retention of clients**

Inadequate retention in HIV care has been associated with suboptimal adherence to antiretroviral treatments, more community viral resistance, increased HIV transmission and poorer survival rates. (Crystal *et al*, 2001). The successful management of HIV disease requires consistent engagement in medical care through lifelong appointments with a physician and uninterrupted medication use. These requirements impose substantial lifestyle adjustments on HIV-positive individuals and their social support networks of family and friends. Members of an HIV patient's social network may remind them of upcoming appointments, provide transportation to the HIV clinic and provide encouragement to continue fighting a heavily stigmatized illness. (Burgoyne, 2005). Alternatively, a number of socio-economic factors may interfere with a patient's ability to engage in regular HIV care. There are several dimensions to these concepts in relation to attendance at HIV clinics but this research set out to investigate these three; transport costs/means to the health unit, financial status and social support.

### **2.3.1 Transportation to Health Unit and Patient Retention**

Since the first large-scale antiretroviral treatment (ART) programs for HIV/AIDS were launched, much attention has focused on patients' day-to-day adherence to antiretroviral medications (Mills, 2006). Long-term retention of patients in treatment programs, a prerequisite for achieving any adherence at all, has received far less attention. A number of studies carried out on retention of HIV patients cited the cost of transportation to obtain ARVs as a major barrier to patient continuity and retention. This has been a major barrier to retention in care in a wide variety of settings in Africa and Asia and other less developed countries of the world.

In Rajasthan (India), among 106 patients who failed to return for 3 or more months, 20% of them cited lack of transportation as the main reason for their failure to return to the health unit (Joshi *et al*, 2008).

In Africa, several studies have presented the lack of transportation among HIV patients on a number of occasions. For example, in western Kenya, one study found that HIV patients' travel time due to lack of transportation was significantly associated with failure of retention among women (OR = 1.07; 95% CI = 1.00–1.16). A similar study of patients in sub-Saharan Africa found out that patients often had to choose between using their limited income on paying for transportation to the clinic versus being able to adequately feed their families (Emenyonu, Muyindike and Habyarimana, 2010). As a result, individuals missed their scheduled clinic appointments and thus not receive their ARVs at the regular time intervals critical for optimal adherence. In rural Malawi, 35% of patients who were lost and traced similarly cited the high cost of transport to the clinic as the reason for absence (Yu *et al*, 2007)..

The International Center for AIDS Care and Treatment (ICAP) performed an independent multisite analysis in Western, Eastern, and Southern Africa using a 6-month absence as the outcome. The study results also presented lack of transportation as a major hindrance which doubled the risk of non-retention in those areas (Rabkin *et al*, 2010)

Studies in Uganda have also presented this as a major barrier to retention. A study in rural Uganda for example, among 111 patients who had been lost to follow-up, the most common reasons for absence were lack of transportation (50%) followed by excessive distance with 42% (Geng *et al* , 2010). A related study among pre-ART patients in Jinja, Uganda indicated that 44% of the patients who were eligible for ART but did not start also cited transportation cost as



the major reason for failure to initiate (Amuron *et al*, 2009).

In a trial, conducted in Mbarara, Uganda, where individuals were randomized to receive a cash refunds of about \$5–\$8 for transportation, only 14 (18%) of the HIV patients under care were lost from the intervention group (Emenyonu *et al*, 2010). This clearly presents the extent to which the cost of transportation affects HIV patient retention among the people of Uganda. This consistent relationship between the cost of transportation and retention has prompted a number of randomised trials studying retention. Kibaale district being majorly rural does not present major divergences from the results above, however the results showed that distance affected the retention of patients at a mild level.

### **2.3.2 Financial status and Patient Retention.**

Financial challenges have been found to prevent adult patients from collecting medication on time. (Skovdal *et al*,2011). Financial challenges in providing ART services in resource-limited settings (RLS) affect retention when service charges are transferred to patients' families – for example, although ART may be supplied free of charge, families may be required to cover other costs such as CD4 and other laboratory monitoring tests. While access to free ARVs was associated with non-adherence in one study (Sarna *et al*, 2008), individuals receiving free treatment may be more likely to be highly impoverished and facing numerous obstacles (e.g., lack of food, shelter) which impact on their ability to adhere (Moss *et al*,2004).

A 2005 meta-analysis focused on ARV programmes in resource-poor settings reported that, in fact, when medications were provided free-of-charge, there was a higher probability of improving retention rates and undetectable viral loads compared to situations where patients were required to pay for treatment (Ivers, Kendrick & Doucette, 2005).

In another study, Oyugi (2007) noted that financial and logistical barriers were affecting drug access which lead to treatment interruption as they were preventing the return of patients to the clinic for follow-up. These barriers in essence affected retention because, retention addresses the processes that may interrupt access to the drugs.

In a South African study, lost patients consistently reported finances as a limiting factor: 34% in a (Maskew, McPhail, Menezes & Rubel, 2007 ) while that for rural Uganda was at 35%.

Lack of finances to buy food in Jimma Zone Ethiopia reported a 17.6% default rate after ART initiation. In this area this has been cited as a reason for poor adherence, and may compromise retention in care as well. (Deribe *et al*, 2008).

With retention rates considerably being determined by financial constraints in many of these developing economies, some measures (though not fully comprehensive) have come up to reduce the burden associated with lack of finances and access to health care by HIV patients.

In Cameroon, the Global Fund supported decentralization of HIV care. A network of district level healthcare facilities with clear guidelines was established, and treatment was largely managed by Doctors, while pharmaceutical companies supported the procurement of generic drugs to reduce costs of ART.

Evaluation revealed that there were higher levels of patient satisfaction on the quality of care received and patient retention at district hospitals compared and with central facilities, particularly due to shorter waiting periods.

MSF in an effort to improve retention rates by maintaining access to care easier financially supported a trial of decentralization in Lesotho. The results depicted considerable success in retaining patients on ART (both adults and paediatrics), with high improvement in retention rates to 76% and 85% for adults and paediatrics respectively (WHO, 2011). Similarly in Rwanda a programme developed with support from Partners in Health (PIH) has resulted in impressive outcomes, with retention rates at 92.3% of people living with HIV/AIDS on ART at 24 months. The findings presented a great need to ascertain the need to consider the magnitude of financial constraints as a great predictor of retention in resource poor economies. The statistics in this study show that financial status affected the retention of patients in Kibaale district but to minor extent.

### **2.3.3 Social Support and Patient Retention**

A growing body of literature highlights the link between strong patient social support systems and receipt of high quality and consistent health care for chronic diseases including HIV. Social determinants of retention in care have also been found to be important in a number of settings.

Ware, Idoko and Kaaya (2010) conducted the largest qualitative study to date in Africa on patterns of accessing care among HIV-infected patients in Nigeria, Uganda, and Tanzania through 252 qualitative interviews. Patients reported that social relationships could help in overcoming barriers to care through the force of social expectations and can also be used to

obtain material benefits that make remaining in care possible.

A similar study in Tanzania based on qualitative interviews with 42 patients revealed that many felt fulfilling responsibility to their children formed a motivating factor for retention in care (Wringe *et al.*,2009). Social support interventions for vulnerable groups appear to be promising interventions to improve retention. In a related study from Kenya, a targeted program providing social support for youths found retention was better at the intervention clinic with 70% remaining in active care versus 55% at the general site for the same age group.

Disclosure (which has been hypothesized to be a marker of social support) was found to be associated with a 70% rise in the odds of retention in 3362 patients in the pMTCT Plus network supported by ICAP (Rabkin *et al*, 2010). Although qualitative interviews from South Africa found stigma did not represent a big challenge to retention, in a study from Malawi, stigma led to non-retention in 45.8% of pre-ART and 25% of on-ART patients (McGuire *et al.*, 2010).

Perceived community stigma can result in non-disclosure of HIV status to social network members and impact received support, health care utilization and medication use. If patients have not disclosed their HIV status to family and friends due to perceived stigma, efforts to hide their disease may impact consistent care-seeking behavior and they may not be able to benefit from potentially available social support.

The failure to communicate their status is a result of what these HIV patients have seen being done to those who disclosed their status before. This is also seen in the number of people who are willing to test for their HIV status as they fear to be targeted by society.

In a cross-sectional study of HIV patients, a positive association was found between social

support and antiretroviral use, but only among those who had disclosed their HIV status. (Waddell & Messeri, 2006). So social support will only come into play if HIV patients disclose their status before hand. A number of patients have fallen victim of stigmatization when they inform their potential care givers in the last phases of the disease. In Kibaale, social support is still lacking among a number of patients independently interviewed and its association with retention was found to be moderate.

## **2.4 Summary**

In this chapter the theoretical perspective of patient behavioural models leading to retention were outlined. The socio-economic factors have been linked to patient retention through literature. Lack of transport among HIV patients on ART was a great predictor of patient retention. On a number of occasions, patients were forced to miss appointments due to shortage of transport to the health unit. However, the shortage of health units is also a great challenge among developing economies. Financial difficulties were also great stumbling blocks to patient retention. In areas where costs were reduced or shared, retention improved but that had to put into consideration other factors like domestic responsibilities especially for women. Social support to patients on ART was also a great factor towards improving retention on condition that patients disclosed their status. In Kibaale district, the magnitude of the effects of the three variables (transport, finances and social support) on retention has been measured by this study.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.0 Introduction;**

Methodology can be defined as the science dealing with the principles of procedure in research and study. This chapter presents the research methodology that was used in this particular study. It outlines the research design, the study area, study population, sample size and selection. The chapter also shows the research design that was adopted,- sampling techniques, procedure of data collection, data collection instruments, pre-testing of the data collection instruments (validity and reliability) and the data analysis methods which were used in the study, as well as the ethical considerations.

#### **3.1 Research Design;**

The researcher adopted a cross sectional survey design so as to assist in determining the degree of relationships that existed between socio-economic variables and patient retention as recommended by Amin (2005). Cross-sectional study is the kind that employs a single point of data collection for each. It proves to be convenient, cheap and not complex and therefore the best for this study. Also this type of design helped a great deal in maximizing the quality of results. This study also adopted the triangulation approach, combining both quantitative and qualitative approaches.

Under this arrangement the elements of biases and subjectivity from the different methods have been greatly minimized, given the fact that each research design compliments the other (Barifaijo *et al*, 2010)

### 3.2 Study Population;

A total of 784 HIV patients who were enlisted for HIV care and treatment between October 2011 and June 2012 at Kagadi Hospital (HMIS 2012) was the study population. The study also included 15 hospital management staff as they would offer relevant information to this study and the sample from these two categories of people was determined by the application of Morgan and Krejcie statistical tables.

### 3.3 Sample size and Selection;

With 784 patients who had been enrolled for HIV Care at this hospital between the period in 3.2 above, these formed the basis for the study’s sample size computation, selection and analysis among patients. The sample size of hospital management staff was determined purposively.

This is further illustrated in **Table 1** below:

Category of respondents	Accessible population	Sample Size	Sampling technique
Hospital Management Staff	15	05	Purposive sampling
HIV Patients	784	260	Systematic sampling
<b>Total Respondents</b>	<b>799</b>	<b>265</b>	

### **3.3.1 Sampling techniques and procedures;**

The researcher adopted systematic random sampling in selection of HIV patients on the list of patients who had been selected from the first patient enlisted and there after every third patient on the list was selected. Systematic sampling is random sampling method with a system from the sampling frame. A starting point is chosen at random, and thereafter at regular intervals. This technique was used in this study because, it minimizes bias in selecting respondents, spreads the sample more evenly over the population and is easier to conduct.

Under the non-probability techniques, purposive sampling was used in selecting senior Hospital management staff and staff in the ART clinic as key informants. Purposive sampling, also commonly called judgemental sampling, is one that is done based on the knowledge of a population and the purpose of the study (Mugenda and Mugenda, 1999:13). This kind of sampling was used because the researcher needed to reach the targeted respondents based on their level of knowledge on the subject matter and their experience with HIV patients in the ART clinic.

### **3.4 Data collection Methods;**

The study used both the quantitative and qualitative methods of data collection (Amin 2005). Some of the qualitative methods that were used in this study include formal and informal interviews (structured). The questionnaires constituted the quantitative method.



### **3.4.1 Questionnaire survey method;**

According to Mugenda (2003), questionnaires are commonly used to obtain important information about the population. Structured questionnaires were given to potential respondents. The questionnaire was the main instrument for collecting data in this particular research and it was interviewer administered. Each item in the questionnaire was developed to address a specific objective, research question or hypothesis of the study. (Mugenda & Mugenda, 2003, 71). Questioning method was helpful in the generation of constructive data. The questioning method offered greater assurance of anonymity hence enabling the respondents to give sensitive information without fear as their identity was not needed.

### **3.4.2 Interviews;**

The researcher also held detailed face to face interviews with ART clinic/hospital management staff. This assisted tremendously in the collection of the respondents' views on the study variables from a management perspective. Semi-structured interviews (Friedman & Wallace 2005) were used to collect data from key informants.

## **3.5 Data collection instruments;**

The study involved the use of various instruments of data collection according to the particular type of information needed (Mugenda and Mugenda, 1999). So the researcher applied the instruments presented and discussed below in the course of study;

### **3.5.1 Structured survey questionnaire;**

The questionnaire survey approach was employed particularly to generate quantitative data for most of the members chosen in the sample size and was the main instrument for generating data

in this study. So the responses were arranged on a **five-point Likert scale**, where 1 represented 'strongly agree' 2 meant 'agree' 3 meant 'Neutral' 4 meant 'disagree', and 5 meant 'Strongly disagree'. This was designed to establish the respondents' level of agreement with the statements. In using this method, each respondent was offered to select the response most suitable to them.

### **3.5.2 Interview guide;**

The researcher also used a semi structured interview guide to get data from key informants and these included mostly those in management at the hospital. This was because such personnel have deeper knowledge of the variables the researcher was studying. The interview guide was structured according to the variables and the objectives of the study. The use of interview guide enabled the researcher to generate more information with greater in-depth on the various questions asked (*Mugenda & Mugenda, 1999*). The Interview guide also made it possible for the researcher to obtain the data to enrich what was captured using the other data collection instruments in the study.

### **3.6 Quality Control;**

Pretesting of the research instruments was done before the massive issuing out of the questionnaires for the purpose of quality control. The researcher was able to get adequate feedback that led to some critical changes in the instrument to ensure clarity and context. Amin (2005) defines validity as being the appropriateness of the instruments to produce findings that are in agreement with theoretical and conceptual issues, while reliability is the consistency of the instruments in measuring whatever it's intended to measure.

### **3.6.1 Validity;**

The researcher had to ascertain how appropriate the instruments were to address the variables under study. The questionnaire and semi-structured interview schedule were equally pre-tested (Mugenda, 2003) so that the researcher's assurance was guaranteed. Content Validity Index (CVI) was used and this was given by the number of items declared valid divided by the total number of items, and for the instrument to be accepted as valid, CVI should be 0.7 or above. The value obtained in this case was 0.832 which was above the recommended value.

### **3.6.2 Reliability;**

All data collection instruments were tried and tested to assess their reliability and dependability. Wherever errors and flaws were identified, necessary adjustments were made to protect the content in the findings. The reliability was measured numerically using the Cronbach's alpha coefficient. Cronbach's alpha is a measure of internal consistency, that is, how closely related a set of items are as a group. A value of 0.721 was obtained which was considered reliable according to (Mugenda, 2003) who declared that a Cronbach value of 0.7 and above was sufficient.

### **3.6.3 Procedure of Data collection;**

Upon approval of the research proposal, a clearance letter was issued from UMI department of Higher Degrees, which was used to introduce the researcher to the area of study. Upon receiving permission, the study immediately kicked off and the collection of data using the above mentioned means/methods commenced.

### **3.6.4 Ethical Considerations**

Ethical issues of consent, confidentiality, openness and explaining the purpose of the research (before collection and afterwards) to the hospital management and the clients were taken into account. Permission was obtained from the district and consent was sought from the clients who acted as respondents to the study.

## **3.7 Data Analysis:**

### **3.7.1 Quantitative analysis;**

The quantitative data collected by the researcher through questionnaires was edited for completeness, accuracy, uniformity and comprehensiveness. It was then converted into numerical codes and analyzed with the help of Statistical Package for Social Scientists (SPSS) version 16.0 (for windows) computer aided program because of its simple usability. Data was thereafter analyzed by way of Spear man's correction coefficient to determine the relationships (Mugenda & Mugenda, 1999). Correlation coefficient and regression analysis were applied so as to test the relationship between the variables.

The relational and inferential statistics from the analysis were used to test the hypotheses in the study.

### **3.7.2 Qualitative analysis;**

Qualitative data obtained through the use of the interviews was thoroughly reviewed, sorted, classified and categorized into themes. The presentation of the above qualitative results was made in verbatim to support findings from the quantitative analysis, which formed the basis for drawing conclusions.

### **3.8 Measurement of variables;**

The measurement scale as it is known for being precise and non-compromising on quality results was used in measuring of the variables in this study (Mthupa (1997a), El-Sakran (1997) and Manjunath et al (1997). So the rating scale that was employed in the research questionnaires was the likert-scale which consisted of numbers as well as the descriptions that helped in rating the subjects and the tangible components in the research (Mugenda, 2003). Therefore the scale comprised of a maximum of 5 response categories as indicated below:

**1= Strongly agree   2= Agree   3= Neutral   4= Disagree   5= Strongly disagree**

## **CHAPTER FOUR**

### **PRESENTATION, ANALYSIS AND INTERPRETATION OF RESULTS**

#### **4.1 INTRODUCTION**

This chapter presents, analyzes and interprets the results. It is divided into six major sections. The first section is the introduction, the second presents the response rate results and the third section presents data on the demographic characteristics of the respondents. It's then followed by results on transport to the hospital and patient retention. The next section relates the financial status of the respondents and patient retention while the final section investigates how the social support affects patient retention in Kagadi hospital.

#### **4.2 RESPONSE RATE**

Response rate (also known as completion rate or return rate) in survey research refers to the number of people who answered the survey divided by the number of people in the sample expressed as a percentage. In this study, the sample was 265 respondents and the study managed to get 226 respondents categorized in the break down table below.

**Table 4.2.1 Response rate**

<b>Category of respondents</b>	<b>Sample Size</b>	<b>Responses</b>	
		<b>Received</b>	<b>Percentage (%)</b>
Hospital Management Staff	05	05	100%
HIV Patients	260	221	85.0%
<b>Total Respondents</b>	<b>265</b>	<b>226</b>	

**Source:** Primary Data

According to Amin, (2005) and Mugenda and Mugenda (1999) the response should be a minimum of 50%. Therefore, the results were considered representative of the population.

### **4.3 DEMOGRAPHIC CHARACTERISTICS:**

The demographic characteristics of respondents considered in this section included: gender, age, education and distance travelled to the health centre.

#### **4.3.1 GENDER**

Information concerning the gender of the patients under HIV care in Kagadi Hospital was collected. The corresponding results were presented in table below.

**Table 4.3.1 Gender of the Patients**

	<b>Gender</b>	<b>Frequency</b>	<b>Percentage (%)</b>
1	Male	82	37.1
2	Female	139	62.9
	Total	221	100.0

**Source:** Primary Data

From the above table, the patients were mainly female with 62.9% while the males constituted 37.1%. The results imply that majority of the patients undertaking HIV care in Kagadi hospital were females. This implies that patient retention in Kagadi hospital will mainly be affected by the behaviour of women towards HIV care as compared to their male counterparts

#### **4.3.2 AGE OF THE LOCAL RESIDENTS**

Age being an important factor in determining the information that a patient will give, data was collected from different age groups from the patients and the results presented in table 4.3.2.



**Table 4.3.2. Age of the Patient**

		<b>Frequency</b>	<b>Percentage</b> (%)
1	Less than 20 years	22	10.0
2	20-30 years	62	28.1
3	31-40 years	65	29.4
4	41-50 years	55	24.9
5	Above 50 years	17	7.7
	Total	221	100.0

**Source:** Primary Data

Statistics from table 4.3.2 indicate that majority of the interviewed patients were between 31-40 years (29.4%) followed by those in the age group 20-30 years (28.1%) and then those between 41-50 years (24.9%). Patients above 50 years and those below 20 years only formed 7.7% and 10% of the patients respectively. This essentially means that HIV care was sought more by middle age groups as compared to the older age groups. The retention of patients is likely to be higher since the majority of the people seeking treatment are strong and still have years to live.

### **4.3.3 HIGHEST EDUCATION ATTAINED**

This demographic characteristic was intended to establish the highest education level attained by the respondents. This would in turn impact on the quality of contributions in the study.

**Table 4.3.3 Highest Education level attained**

	<b>Education level</b>	<b>Frequency</b>	<b>Percentage (%)</b>
1	None	35	15.8
2	Primary	146	66.1
3	O level	38	17.2
4	A level / Certificate	1	.5
5	Diploma	1	.5
	Total	221	100.0

**Source:** Primary Data

As evidenced from table 4.3.3, the highest number of respondents (66.1%) had attained up to primary level followed by those who had attained O-level education (17.2%) and a reasonable 16% had attained no education at all. Those that had gone up to A level only constituted 0.5%. This means that the average level of education of people in the area is relatively low. This is likely to negatively impact on the retention of patients since low education levels are associated with low levels of awareness on a number of health issues.

#### **4.3.4 DISTANCE TRAVELLED TO THE HEALTH CENTRE**

Information was also collected from the respondents concerning the distance they travelled to reach Kagadi Hospital. This being one of the factors that are likely to affect retention of patients, the results on the distance travelled were considered of utmost importance. Table 4.3.4 below shows the details.

**Table 4.3.4 Distance travelled to the health centre**

		<b>Frequency</b>	<b>Percentage (%)</b>
1	Less than 1 Mile	20	9.0
2	Between 1 and 5 Miles	68	30.8
3	Between 5 to 10 Miles	70	31.7
4	Over 10 Miles	63	28.5
	Total	221	100.0

Results show that majority of the patients travelled between 5-10 miles (31.7%) followed by those between 1 and 5 miles (31.7%) and then those that travelled over 10 miles constituted (28.5%). On average, patients travelled very long distances to reach the health centre which is likely to affect utilization of HIV care services especially for those that are in critical conditions. Patient retention at the health centre is likely to be affected negatively since most of the patients travel long distance to seek HIV care.

#### **4.4 TRANSPORT TO THE HOSPITAL AND PATIENT RETENTION**

In this study, descriptive statistics (frequencies and percentages) were presented first for each of the objectives and then inferential statistics in form of Spearman correlation, coefficient of determination were computed and interpreted as shown below.

##### **4.4.1 DESCRIPTIVE RESULTS ON TRANSPORT TO THE HOSPITAL**

To analyze the findings, descriptive statistics on the respondents who strongly agreed and those

who agreed were run for each variable. Similarly, descriptive statistics for those who were neutral, those who strongly disagreed and those who disagreed were also run. Interpretation was then drawn from the comparisons of the five categories.

**Table 4.4.1. Findings on Transport to the Hospital**

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	The transport costs to the health facility are a burden	48.0%	33.0%	.0%	16.3%	2.7%
2	Sometimes transport costs are met at the cost of other family needs	39.4%	38.0%	2.3%	18.1%	2.3%
3	A reduction in transport costs will improve on your attitude towards ART	54.3%	39.4%	4.5%	1.4%	.5%
4	There are transport refunds towards your ART attendance	.5%	.0%	.5%	13.6%	85.5%
5	The absence of transport funds often makes you miss appointments	24.4%	26.7%	.5%	35.3%	13.1%
6	The means of transport to the health facility are inadequate	12.7%	24.9%	.5%	49.8%	12.2%
7	Poor transport means to the health facility are major determinants of ART failure	15.4%	31.7%	16.3%	33.5%	3.2%
8	Many HIV patients have died because of the lack of transport means	27.1%	38.9%	13.1%	17.6%	3.2%

**Source:** Primary Data

Study results show that transport costs to the health facility were a great burden to clients (strongly agreed (48%), agreed (33%)). The results also show that a reduction in transport costs would greatly improve the attitude towards Anti Retroviral Treatment attendance as 54.3% strongly agreed, 39.4% agreed, 4.5% were neutral 1.4% disagreed while 0.5% strongly

disagreed. This means that patients were facing a transport cost burden and would be more interested in seeking HIV care if the burden was reduced. In addition, majority of the patients affirmed that a number of patients had died because of lack of transport. Results show that 27.1% strongly agreed while 38.9% agreed. In addition, 13.1% were neutral, 17.6% disagreed while 3.2% strongly disagreed. This means that transport burden and its associated costs would lead to many patients delaying to seek treatment, failing to seek treatment and some dying. This implies the numbers to be retained at the hospital will reduce.

The results concur with the findings from interviews with the key informants. All of them cited the inadequacy of the transport means to the hospital. They cited that most patients came from long distances with extremely bad roads and a number of those places had no taxis and so they resorted to using motor cycles (Bodabodas) which were extremely expensive. One of the officers who work in the Early Infant Diagnosis (EID) was quoted to say:

*Many clients use boda bodas (those who can afford). Many walk to the hospital and generally the majority of the clients move long distances (some from lake shores of Albert-which is over 40 km) and this is the reason some of them request for drugs that last for 2 months, while others send their friends to pick for them drugs*

(Key Informant 3).

This means those who cannot walk and those who cannot afford boda bodas end up failing to turn up for the scheduled appointment dates which leads to an increment in the number of people dropping out of HIV Care thus affecting patient retention at Kagadi hospital.

The study also revealed that 39.4% strongly agree while 38.0% agree that sometimes transport costs are met at the cost of basic family needs.

On the other hand 18.1% disagreed, 2.3% strongly disagreed while 2.3% were neutral. This means that many patients find themselves starving their families in order to attain medication. If this is repeating, the absence of regular incomes leads to an increase in the number of HIV patients dying because of their inability to access treatment. It implies that the number of patients being retained at the hospital is going to reduce.

#### 4.4.2 DESCRIPTIVE RESULTS ON PATIENT RETENTION

**Table 4.4.2 Findings on Patient Retention:**

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	Retention of patients under HIV care is still a major challenge in this area	15.4%	57.5%	6.3%	17.6%	3.2%
2	The authorities at the health facility are doing their best to improve the retention of their patients under HIV care.	49.8%	34.4%	14.9%	.5%	.5%
3	Many patients try to do their best to stay on ART but fail because of unavoidable circumstances.	32.6%	55.2%	10.4%	1.8%	.0%
4	The cost of retaining patients in this community is high	15.4%	40.3%	25.8%	18.1%	.5%
5	Retention of patients under HIV care should be seriously addressed by the ministry of health	50.2%	45.2%	4.1%	.5%	.0%
6	Majority of the retained patients are still willing to stay on ART.	67.0%	31.7%	.9%	.0%	.5%
7	You are still attending ART mainly because ARVs are free.	86.0%	8.6%	.9%	4.1%	.5%
8	Stigma has reduced on the number of patients receiving HIV care	38.0%	28.5%	.5%	22.6%	10.4%

Study results from the table above show that retention of patients was still a major challenge in the area as 15.4% strongly agreed to this while those that agreed comprised of 57.5%. Those with a neutral response made 6.3% of the respondents, 17.6% disagreed while 3.2% strongly disagreed. The results imply that there was a general problem as far as retention of the patients was concerned. An interview with the key informants revealed similar reports as the majority cited that there was still a problem with retention of patients especially those on pre-ART. One officer at the ART clinic was quoted saying:

*Most of the patients on ART do come and keep appointments.....The newly enrolled [especially those on pre-ART] are given drugs for 2 weeks as they need to be regularly monitored but after some time a number of them disappear. The majority of the lost clients are those on pre ART.*

(Key Informant 2)

There is therefore need to reinforce follow up of the clients on pre ART and new clients and strongly establish the main reasons behind their high drop out rates in order to increase patient retention and reduce on the number of HIV patients dying in the area.

Another respondent was quoted to have said that:

*Some clients are getting lost. It is a problem at the hospital and those who are working there like us, it affects us because we would love these people to come for support like counseling. (Key informant 5)*

As highlighted above, this cites poor or inadequate patient follow up by the hospital authorities which need to be addressed if the number of patients retained at the hospital is to be kept relatively high.

However, the study results also reveal that the authorities were trying their best to improve on the retention of patients. Evidence shows that majority (49.8%) strongly agreed, 34.4% agreed, 14.9% were neutral, while 1% generally disagreed. Similarly, the study reveals that 98.6% of the patients that had been retained were still willing to stay in HIV care and treatment. This means that other factors may be responsible for the patients' low retention but both parties (the patient and the hospital authorities) were doing their best to improve retention.

The study also reveals that 67% of the patients strongly agreed and 31.7% agreed that they were willing to stay on ART as long as the ARVs were free. This implies that providing free drugs was a key factor in improving the number of patients retained at the Hospital.

### **4.3.3 TESTING THE FIRST HYPOTHESIS**

The first hypothesis stated, *There is a significant relationship between transport to the hospital and retention of HIV clients in care and treatment..* Spearman's correlation coefficient (*rho*) was used to determine the strength of the relationship between transport to the hospital and patient retention. The coefficient of significance (*p*) was used to test the findings by comparing *p* to the critical significance levels at (0.05). This procedure was applied in testing the second and third hypotheses.



**Table 4.3.3 Correlation between Transport to the hospital and Patient retention**

			Transport to the hospital	Patient retention
Spearman's rho	Transport to the hospital	Correlation Coefficient	1.000	.210*
		Sig. (2-tailed)	.	.002
		N	221	221
	Patient retention	Correlation Coefficient	.210*	1.000
		Sig. (2-tailed)	.002	.
		N	221	221

\*. Correlation is significant at the 0.05 level (2-tailed).

The findings show low correlation ( $\rho = 0.210$ ) between transport to the hospital and patient retention. The corresponding coefficient of determination ( $\rho^2 = 0.0441$ ) was computed implying that transport to the hospital accounts for just 4.4 % influence in patient retention. A corresponding p-value 0.02 was obtained which is lower than the recommended standard p value of 0.05. This confirms that the effect of one variable on the other was significant though small. Conclusively, the hypothesis *Transport to the hospital has got a positive relationship on patient retention was accepted*. The findings implied that the distance HIV patients travel to seek care and treatment at the health centre to a small degree affects the retention of the patients at the health centre. This meant that HIV patients who came from distances nearer to the health centre were most likely to be retained as compared to those that came from longer distances. Evidence from some of the key informants were cited saying patients would go an extra mile to use up to 20,000 UGX on a motor cycle just to make it for the appointment.

This was evident among those that came from longer distances.

On a particular day when facilitation would not be obtained, many would miss appointments which results into patient weakening and eventually dropping out.

## 4.5 FINANCIAL STATUS AND PATIENT RETENTION

### 4.5.1 DESCRIPTIVE RESULTS ON FINANCIAL STATUS

The items presented under this variable were eight (8) and the corresponding descriptive statistics are presented in table 4.5.1 below.

**Table 4.5.1 Findings on Financial status**

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	Financial challenges prevent many patients from collecting medication in time.	29.9%	57.0%	1.8%	11.3%	.0%
2	The Access to free ARVs is a major boost to your attendance	78.7%	20.4%	.0%	.5%	.5%
3	There is a stable monthly income in your family.	2.3%	9.5%	.0%	46.2%	42.1%
4	When personal incomes improve, your ART attendance is simplified	60.2%	39.4%	.5%	.0%	.0%
5	In this area, poor patient attendance is a result of the lack of stable incomes by the HIV patients	24.0%	51.6%	8.6%	14.0%	1.8%
6	Income generating projects should be generated for patients under HIV care.	85.1%	14.9%	.0%	.0%	.0%
7	Financial challenges are a major cause of the death of many patients under HIV care	30.3%	48.0%	12.7%	8.1%	.9%
8	Many families have to forego a number of essential family needs in order to meet appointments for HIV care	36.2%	48.0%	4.1%	10.9%	.9%

**Source:** Primary Data

Results from the table above show that 57.0% of the patients affirmed that financial challenges would prevent many of them from collecting medication in time while 29.9 % strongly agreed. Those that were neutral only constituted 1.8% of the respondents while those who strongly disagreed accounted for 11.3%. Similarly financial challenges were identified as a major cause of death for patients seeking HIV care as (48.0%) agreed while 30.3% strongly agreed. The neutral responses constituted 12.7% of the responses while 8.1% disagreed. Also 99.5% affirmed that the improvement in the incomes would eventually improve ART attendance while 0.5% were neutral. This means that the financial status of the person seeking treatment had a strong attachment to their levels of attendance. It implies that financial challenges were bound to reduce the number of patients regularly attending treatment which eventually affects the number of patients retained.

The study results concur with the findings from the key informants. All of them cited the high poverty levels in the area being a major problem identified in majority of their clients. One respondent said most of the patients were not working as they used to do because of general body weakness. This led to low incomes in the households involved. Another respondent was quoted saying:

*“Financial challenges are a hindrance because it makes the patients not keep their appointments. If they miss appointments, they do not adhere to drugs and this leads to development of resistance to drugs. TASO used to provide tea on clinic days but this stopped. Some clients come without any thing to eat/drink yet the hospital does not allow anyone to sell any food items in the hospital. Even those who have some money decide to move to town to buy something to eat, they become a problem as a “clinician will call and the clients are not around” (Key informant 2).*

A mixture of strict administrative policies and the absence of enough finances greatly affect the retention of patients. If the hospital would lobby for some facilitation for its patients and also

adjust its policies on food, the number of patients attaining treatment would eventually improve.

The provision of mobile health units to areas close to where patients stayed would also boost on the intake of HIV care services.

It therefore implies that increasing the number of patients attending HIV services would significantly impact on the number of HIV patients that are likely to be retained.

**4.5.2 TESTING OF THE SECOND HYPOTHESIS:**

A table of correlation is presented below which shows the degree to which the patient’s financial status affects the retention of the patient at the health centre.

**Table 4.5.2 Correlation between Financial status and Patient retention**

			<b>Financial status of patient</b>	<b>Patient retention</b>
Spearman's rho	<b>Financial status of patient</b>	Correlation Coefficient	1.000	.243**
		Sig. (2-tailed)	.	.000
		N	221	221
	<b>Patient retention</b>	Correlation Coefficient	.243**	1.000
		Sig. (2-tailed)	.000	.
		N	221	221

\*\* . Correlation is significant at the 0.01 level (2-tailed).

Findings show that there was a weak positive correlation ( $\rho = 0.243$ ) between the patient's financial status and the retention of patients at the health centre. The corresponding coefficient of determination ( $\rho^2 = 0.0429$ ) was computed and expressed as a percentage to determine the variance in patient retention due to their financial status.

Thus, findings indicated that the financial well being of the residents accounted for 6.0% variance in patient retention.

These findings were then subjected to a test of significance ( $p$ ) and results indicated that the significance of the correlation ( $p = 0.00$ ) was below the recommended critical significance at 0.01 (2-tailed). Thus, the effect was significant. Therefore, the hypothesis "*The financial status of the patient affects their retention in HIV care and treatment*" was accepted. The implication of these findings is that the finance status of the HIV patients seeking care and treatment affects their retention at the health centre. The low correlation implied that an improvement in incomes would eventually improve retention at the health centre to a small extent. The low relationship could be attributed to the fact that despite the financial challenges, patients would try their best to keep their appointments. The fact that drugs are free could also be the other factor that keeps the patients coming which keeps the retention levels under check.

## **4.6 SOCIAL SUPPORT AND PATIENT RETENTION**

### **4.6.1 DESCRIPTIVE STATISTICS ON SOCIAL SUPPORT.**

Information was collected on social support offered to patients and the items were identified and table 4.6.1 below presents the overview of the results.

**Table 4.6.1 Findings on Social Support**

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	Social relationships with patients under HIV care are very important	59.7%	38.5%	.5%	1.4%	.0%
2	Disclosure of your HIV status was not a major problem.	30.3%	33.9%	.9%	22.6%	12.2%
3	Your family are providing nutritional support for you	17.2%	44.8%	.0%	32.1%	5.9%
4	The absence of nutritional support to many patients has led to their death	29.9%	48.9%	15.4%	4.1%	1.8%
5	Many HIV patients under ART are facing nutritional challenges	33.5%	50.7%	12.2%	3.2%	.5%
6	Your family is providing the emotional care you need	31.7%	42.1%	1.4%	18.1%	6.8%
7	Perceived community stigma can result in non-disclosure of HIV status to social network	33.5%	52.5%	1.8%	10.9%	1.4%
8	Failure to disclose one's HIV status in time can affect the emotional care provided to the patients	30.3%	54.8%	2.7%	11.3%	.9%

The study results from the table above show that the patients valued social relationship as 59.7% of them strongly agreed. Those that agreed accounted to 38.5% of the HIV patients while those that were neutral comprised of a negligible 0.5%. This means that social relationships with the clients are an integral part of their HIV care program meaning they play a great role in their day today living. It therefore implies that providing the necessary social support would therefore improve on the number of patients joining HIV care which would significantly improve on the numbers retained.

In Kagadi area, a good number of the patients were said to have got the social support through AIDS community volunteers (ACVs) who gave health talks on positive living according to an interview with one officer in the Early Infant Diagnosis (EID) clinic. The officer noted that the ACVs also live in communities and give sessions on acceptance/stigma for people to fit in communities but these volunteers were very few. It was also noted that the volunteers and health workers in the clinic were always ready to give support/health talks on – disadvantages of not attending clinics/missing clinic appointments, importance of adherence among others.

Asked on how many of them received emotional care from their family members, majority (73.8%) of the respondents affirmed that they did, while only 24% of them did not. A very negligible 1.4% remained neutral on the subject. Similarly, 62% affirmed that they received nutritional support from their families. The respondents pointed out that the absence of nutritional support had led to the death of many patients under HIV care and treatment. This re-affirmed the importance of nutritional care for HIV patients as the absence thereof was likely to lead to the death of many. It implies that the social support provided to the patients would eventually increase the number of patients retained under HIV care.

*One HCT counsellor in an interview on the state of social support in the area and how it has affected retention said that TASO stopped supporting the clinic with free milk, sugar and posho about 8 years ago. So a number of patients remained at their homes to look for survival through gardening, and also looking for school fees. This was likely to lead to missed appointments and thus poor retention.*

(Key Informant 5)

This suggests that dropout of free provision of additional nutrients did not affect the number of HIV Patients being retained but also those that were joining the program. This implies that if adequate attendance and retention of HIV patients under care was to be realised, free food supplements should be a compounding factor and adequate efforts need to be made by the hospital authorities to attain them.

#### 4.6.2 TESTING OF THE THIRD HYPOTHESIS

The table below shows the extent to which social support accorded to the patient affects the retention of patients at the health centre. It measures the degree to which these two variables are correlated.

**Table 4.6.2 Correlation between Social Support and Patient retention**

			<b>Social support to patient</b>	<b>Patient retention</b>
Spearman's rho	<b>Social support to patient</b>	Correlation Coefficient	1.000	.214*
		Sig. (2-tailed)	.	.001
		N	221	221
	<b>Patient retention</b>	Correlation Coefficient	.214*	1.000
		Sig. (2-tailed)	.001	.
		N	221	221

\*. Correlation is significant at the 0.05 level (2-tailed).

**Source:** Primary Data

In order to ascertain the relationship between social support and patient retention, the spearman's correlation coefficient (*rho*) was run and the value obtained above (*rho* = 0.214) shows that there



is weak correlation between social support and patient retention.

Otherwise stated, social support accounts for a low percentage in patient retention (4.6%).

Subject to a test of significance, a p value of 0.001 which is less than the standard p value of 0.05 (two-sided) re-affirms that social support is important if HIV patients under care are to be retained but to a small extent. Therefore the hypothesis that *the social support accorded to the patient has an effect on their retention in HIV care was accepted.*

This essentially means that despite the importance of social support to patients under HIV care, its improvement will increase retention of HIV patients at the health centre by a small margin. This could be attributed to a number of other factors like the poverty levels in the family among others. In an event where poverty levels are reduced, social support might be embraced even more.

## **CHAPTER FIVE**

### **SUMMARY, DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

This chapter presents the summary, discussion, conclusions and recommendations. It is divided into six major sections. The first section is introduction, the second section presents the summary and the third section presents the discussion. Fourth, fifth and sixth sections present the conclusions, recommendations and areas of future research respectively.

#### **5.2 SUMMARY OF MAJOR FINDINGS**

The purpose of the study was to find out effects of socio-economic factors on HIV patient retention under care and treatment in Kagadi hospital. Presented here is the summary of the findings based on the objectives of this research.

##### **5.2.1 TRANSPORT TO THE HOSPITAL AND RETENTION OF PATIENTS UNDER HIV CARE.**

The findings revealed that transport costs to the hospital were a great burden to the patients seeking HIV care as a number of them used motor cycles (boda boda) to come to the health facility. The study also revealed that the transport means to the hospital were not so adequate as most of the rural roads were very poor. Transport to the health centre affected retention of patients at minor level ( $\rho = 0.210$ ,  $P = 0.02$ ) because the patients would forego anything to pick drugs.

## **5.2.2 FINANCIAL STATUS AND PATIENT RETENTION.**

The findings in this study revealed that financial challenges affected most of the patients under HIV care from collecting medication in time (86.9%). However, this did not directly affect their retention. Access to free ARVs was a major boost to the attendance of patients (99.1%) and this would eventually culminate into their retention. Generally, the financial status of the patients affected their retention at Kagadi hospital but to a minor level ( $\rho = 0.243$ ,  $P = 0.000$ )

## **5.2.3 SOCIAL SUPPORT AND PATIENT RETENTION**

The study findings revealed that social relationships with patients receiving HIV care were of great significance. Majority of the patients receiving HIV care were facing nutritional challenges since TASO pulled out of providing food to HIV patients 8 years ago. From a general perspective, social support offered to HIV patients minimally improved the retention of HIV patients as compared to the absence thereof. ( $\rho = 0.214$ ,  $P = 0.001$ )

## **5.3 DISCUSSION OF RESULTS**

### **5.3.1 TRANSPORT TO THE HOSPITAL AND PATIENT RETENTION**

The first hypothesis stated, *There is a significant relationship between transport to the hospital and retention of HIV clients in care and treatment.* The Spearman correlation index indicated a low correlation between these two variables. It was clearly seen that transport to the hospital to some extent affected the ability of the patient to stay under HIV care. The findings in this study concur with a number of earlier researches comparing distance travelled and retention of patients under HIV care. A study in rural Uganda, among 111 patients lost to follow-up, excessive distance was cited among the major reasons for poor retention (42%).

Similar challenges related to accessing quality HIV care and retention are typically amplified as well in rural areas in the US (Moneyham et al.,2010). A similar study by Beardsley et al.,(2004) assessing the effect of distance travelled on patient retention from an urban setting noted that clients who travelled less than 1 mile were 50% more likely to complete treatment than clients who travelled more than 1 mile. Similarly, clients who travelled more than 4 miles were significantly more likely to have a shorter length of stay than clients who travelled less than 1 mile.

The similarities are a result of the fact that most of these settings whether urban or rural are occupied by low income earners and these areas often don't have the best network of health centers. These findings have important implications for the geographic placement of the treatment facilities for patients under care, as well as the provision of transportation services to maximize patient retention. It however remains a challenge as to whether the bringing of health services nearer to the patients can be implemented in the short run to solve the distance and transport problem that the patients face.

The study results also revealed that transportation costs affected the retention of patients at Kagadi hospital. Studies in other areas of Uganda have also presented this as a major barrier to retention. For example, in a study in a rural setting among 111 patients who had been lost to follow-up, the most common reasons for absence were lack of transportation (50%) (Geng *et al* , 2010). A related study among pre-ART patients in Jinja, indicated that 44% of the patients who were eligible for ART but did not start also cited transportation cost as the major reason for failure to initiate (Amuron *et al*, 2009).

A similar study, in western Kenya, found that HIV patients, travel time due to lack of transportation was significantly associated with failure of retention among women (OR = 1.07; 95% CI = 1.00–1.16). In Rajasthan (India), among 106 patients who failed to return for 3 or more months, 20% of them cited lack of transportation as the main reason for their failure to return to the health unit (Joshi *et al*, 2008). In rural Malawi indicated that 35% of the patients who had been lost and traced cited high cost of transportation to the clinic as the reason for absence (Yu *et al*, 2007).

The findings though all present transportation cost as a challenge, the percentages differ greatly from one country to another. It is clear that the magnitude of the problem in Uganda and Malawi for example was higher than that of India. The difference is that the area in India where the research was carried out was more of an urban setting as compared to the scenario in the African countries. However, the question of transportation being a major barrier to retention of patients under care cannot be underestimated though in this study the transportation costs do not automatically lead to their dropout. What remains unresolved is the mechanism through which the health centres can reduce on the costs associated with transport given the limited income settings in the developing economies.

### **5.3.2 FINANCIAL STATUS AND PATIENT RETENTION.**

The study also revealed that 86.9% of the patients highlighted that financial challenges prevented many of the patients from collecting medication in time. The results concur with those of a similar study by Skovdal *et al*. (2011).

They explain that financial challenges in providing ART services in resource-limited settings affect retention when service charges are transferred to patients' families – for example, although ART may be supplied free of charge, families may be required to cover other costs such as CD4 and other laboratory monitoring tests.

In another study, Oyugi (2007) noted that financial and logistical barriers were affecting drug access which led to treatment interruption as they were preventing the return of patients to the clinic for follow-up. These barriers in essence affected retention because, retention addresses the processes that may interrupt access to the drugs.

In a South African study, lost patients consistently reported finances as a limiting factor: 34% in a (Maskew, McPhail, Menezes & Rubel, 2007 ) while that for rural Uganda was at 35%. Lack of finances to buy food in Jimma Zone Ethiopia reported a 17.6% default rate after ART initiation. In this area this has been cited as a reason for poor adherence, and may compromise retention in care as well. (Deribe *et al*, 2008).

However despite the above challenges, a number of countries even in the developing nations of Africa have come up with methods where financial challenges are not the major factor behind driving patients out of HIV care. In Cameroon for example, the Global Fund supported project on decentralization of HIV care project resulted into higher levels of patient satisfaction, high quality of care received and patient retention rates at district hospitals. Under this scheme, financial challenges were barely the reason behind those that were dropping out of HIV care.

Similarly, in Rwanda a programme developed with support from Partners in Health (PIH) resulted into impressive outcomes, with retention rates at 92.3% of people living with HIV/AIDS on ART at 24 months, financial challenges were barely mentioned here as well.

The reason behind the similarities and differences has a lot to do with the management framework in the respective countries. The policy on drug procurement and administration creates a major difference on the out comes in the different countries. It also has to do with the patient-physician ratio as many of the HIV patients don't want to wait long in the ques. It is therefore conclusive that the financial challenges affect the retention of patients under HIV care but the magnitude to which it does is a factor of the framework of effective administration in the different countries. What remains unresolved is how the individual incomes of the patients can be improved despite the subsidies given to them when under HIV care.

The second hypothesis stated, *financial status of the patient affects their retention in HIV care and treatment*. Spearman correlation index indicated that a low correlation existed between the financial status of the people and their retention in HIV care. However this does not remove the fact that financial challenges are common to patients seeking HIV care and treatment. It only means that not all patients facing financial challenges drop out of HIV care. Most of the patients in this study stated that; *access to free ARVs was a major boost to their attendance*. Similar results were obtained in a study by Ivers, Kendrick & Doucette (2005).

They argued that when medications were provided free-of-charge, there was a higher probability of improving retention rates and undetectable viral loads compared to situations where patients were required to pay for treatment. The challenge remains that in a number of LDCs the drugs have been provided free but the number of those dropping out of HIV care is still increasing.

### **5.3.3 SOCIAL SUPPORT AND PATIENT RETENTION.**

The outcomes of this study indicated that *social support had a weak positive relationship with patient retention under HIV care*. This meant that social support though significant did not automatically lead to the drop out of the patients seeking HIV care and treatment.

However some studies reveal that social support interventions for vulnerable groups appear to be promising interventions to improve retention. For example in a study from Kenya, a targeted program providing social support for youths found retention was better at the intervention clinic with 70% remaining in active care versus 55% at the general site for the same age group. Another qualitative study by Ware, Idoko and Kaaya (2010) on patterns of accessing care among HIV-infected patients in Nigeria, Uganda, and Tanzania revealed that social relationships could help in overcoming barriers to care through the force of social expectations.

A similar study in Tanzania based on qualitative interviews with 42 patients revealed that many felt fulfilling responsibility to their children formed a motivating factor for retention in care (Wringe *et al.*,2009). Social support interventions for vulnerable groups appear to be promising interventions to improve retention. Despite the fact that social behaviour differs from one society to another, and from one country to another, the similarities in culture and social norms on the African continent cannot be denied.



The study also found out that failure to disclose one's HIV status in time could affect the emotional care provided to the patients (85.1%). Rabkin *et al*, (2010) found out that disclosure (which has been hypothesized to be a marker of social support) was found to be associated with a 70% rise in the odds of retention in 3362 patients in the pMTCT programme. Perceived community stigma was seen to be a result in non-disclosure of HIV status to social network members and impact received was support, health care utilization and medication use. If patients have not disclosed their HIV status to family and friends due to perceived stigma, efforts to hide their disease may impact consistent care-seeking behavior and they may not be able to benefit from potentially available social support. (McGuire *et al*,2010). Despite the sensitization campaigns, the behaviour of some societies towards HIV patients can be unbearable. The decision not to disclose one's status is conclusively based on the anticipated fears of stigma.

## **5.4 CONCLUSIONS**

In view of the findings of this study, and in regard to the literature reviewed earlier, the researcher made the following conclusions.

### **5.4.1 TRANSPORT TO THE HEALTH CENTRE AND PATIENT RETENTION.**

The transport costs and distance travelled to the Hospital were a great barrier for patients under HIV care. These engage them into practices like hiring bodabodas in order to attain treatment sometimes at the expense of other necessary needs of the family. This can eventually alter the progress of the family economically and socially. Transport means to the health facilities in a number of developing countries are a major problem as well as the costs to do with the available means even when drugs are free.

#### **5.4.2 FINANCIAL STATUS AND PATIENT RETENTION.**

Financial challenges are a major problem facing patients undertaking HIV care and treatment especially when service charges are transferred to the patients. Costs like laboratory costs and CD4 count still affect patients in developing countries even when they look minimal which affects the retention of patients. So poverty remains a great factor affecting retention of patients in developing nations.

#### **5.4.3 SOCIAL SUPPORT AND PATIENT RETENTION**

Social support contributed to disclosure and therefore retention in a number of studies in Africa. Issues to do with the disclosure of the patient's status to the friends and family were key players in retaining patients under care. In a case where patients did not disclose their HIV status to family and friends due to perceived stigma, efforts to hide their disease would eventually impact on their consistent care-seeking behaviour and they may not be able to benefit from potentially available social support.

### **5.5 RECOMMENDATIONS**

The recommendations for this study took into account all the views and opinions of the respondents in the study that are summed up in the findings of the study.

#### **5.5.1 TRANSPORT TO THE HOSPITAL AND PATIENT RETENTION**

The government of Uganda through the ministry of health should further decentralise HIV care services through accrediting lower level health facilities (especially health centre IIIs) to offer ART services as this will improve on accessibility and utilisation of these services.

### **5.5.2 FINANCIAL STATUS AND PATIENT RETENTION.**

There should be support to the patients in terms of transport refunds to the patients seeking HIV care and treatment as this would reduce their family burden as some were seen to forego a number of essential family needs in order to obtain treatment. There is also need to involve men as they can give/provide transport to their partners in the case of female patients.

### **5.5.3 SOCIAL SUPPORT AND PATIENT RETENTION.**

The government should deepen its campaigns against stigma to the rural areas in a more practical sense. Many HIV positive patients fear seeking treatment because of the fear of being identified (stigma) and a number of those that start to drop out of HIV care after people discover who their HIV status.

Awareness campaigns should be taken to the grassroots and more often. Also physical follow up of clients should be emphasized as there was need to talk to family members as well for example children, spouses and siblings. Intensifying of sensitization through drama should be re-emphasized as it is a good mobilization instrument.

## **5.6 AREA FOR FURTHER RESEARCH**

Although the study was primarily based on socio-economic characteristics and patient retention, there is need to study the health service system factors, and quality issues in the ART clinic at Kagadi Hospital. In addition, there is need to investigate more on patients who delay to seek treatment as a number of people may not necessarily drop out but will be victims of the socio-economic conditions. Also other factors that affect retention of patients especially in rural areas should be studied.

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## APPENDIX I

### UGANDA MANAGEMENT INSTITUTE

#### QUESTIONNAIRE TO HIV PATIENTS:

**TOPIC: SOCIO-ECONOMIC CONDITIONS AND RETENTION OF CLIENTS IN  
HIV CARE AND TREATMENT AT KAGADI HOSPITAL**

The main purpose of the study is to find out the role of socio-economic conditions on retention of patients under HIV care. You are humbly requested to fill this questionnaire with the information needed to make this study successful. I guarantee that all the responses obtained in this questionnaire will be treated with strict confidentiality and used only for academic purposes.

#### **Instructions**

For section A, Tick (✓) in the most appropriate box where necessary.

#### **SECTION A: Background information of the respondent**

1. Gender

- a. Male                      b. Female

2. Age

- a. Below 20 years      b. 20 – 30 years      c. 31 - 40 years  
d. 41 – 50 years      e. Above 50 years

3. Marital status

- a. Single   b. Married   c. Divorced   d. Widowed.   E. Others (specify)

4. Level of education
- a. None      b. Primary      c. O level      d. A Level/Certificate
- e. Diploma      f. Graduate      g. Post graduate
5. Current occupation
- a. None      b. Peasant      c. Self employed
- d. Employed
6. Distance to the health facility
- a. Less than 1 mile      b. Between 1 and 5 Miles
- c. Between 5 to 10 Miles      d. Over 10 miles
7. Main means of transport to the health facility:
- a. Walk      b. Bicycle      c. Motorcycle
- d. Taxi/Bus      e. Self-driven      f. Other
8. Treatment type
- a. Pre-ART (Septrin)      b. ART

**Instructions: For Sections B, C, D and E below, tick (✓) the most appropriate option where applicable in the space provided. The questions have codes ranging from 1 to 5 as seen below.**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>Scale</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>No Opinion</b>	<b>Disagree</b>	<b>Strongly Disagree</b>

**Section B: Transport to the health facility.**

	Objective Area	Options				
		1	2	3	4	5
	<b>Transport to the health facility</b>					
1	The transport costs to the health facility are a burden					
2	Sometimes transport costs are met at the cost of other family needs					
3	A reduction in transport costs will improve on your attitude towards ART					
4	There are transport refunds towards your ART attendance					
5	The absence of transport funds often makes you miss appointments					
6	The means of transport to the health facility are inadequate					
7	Poor transport means to the health facility are major determinants of ART failure					
8	Many HIV patients have died because of the lack of transport means to the health facility					

### Section C: Financial Status of the respondent

	Objective Area	Options				
		1	2	3	4	5
	<b>Financial status</b>					
1	Financial challenges prevent many patients from collecting medication in time.					
2	The Access to free ARVs is a major boost to your attendance.					
3	There is a stable monthly income in your family.					
4	When personal incomes improve, your ART attendance is simplified					
5	In this area, poor patient attendance is a result of the lack of stable incomes by the HIV patients					
6	Income generating projects should be generated for patients under HIV care.					
7	Financial challenges are a major cause of the death of many patients under ART.					
8	Many families have to forego a number of essential family needs in order to meet appointments for ART.					

**Section D: Social Support to the Patient**

	<b>Social Support to the Patient</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
1	Social relationships with patients under HIV care are very important					
2	Disclosure of your HIV status was not a major problem.					
3	Your family are providing nutritional support for you					
4	The absence of nutritional support to many patients has led to their death.					
5	Many HIV patients under ART are facing nutritional challenges.					
6	Your family is providing the emotional care you need.					
7	Perceived community stigma can result in non-disclosure of HIV status to social network					
8	Failure to disclose one's HIV status in time can affect the emotional care provided to the patients					

**Section E: Patient Retention**

	<b>Patient Retention</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
1	Retention of patients under HIV care is still a major challenge in this area.					
2	The authorities at the health facility are doing their best to improve the retention of their patients under HIV care.					
3	Many patients try to do their best to stay on ART but fail because of unavoidable circumstances.					
4	The cost of retaining patients in this community is high					
5	Retention of patients under HIV care should be seriously addressed by the ministry of health.					
6	Majority of the retained patients are still willing to stay on ART.					
7	You are still attending ART mainly because ARVs are free.					
8	Stigma has reduced on the number of patients receiving HIV care					

**Thank you.**



## **APPENDIX II**

### **UGANDA MANAGEMENT INSTITUTE**

#### **INTERVIEW GUIDE TO KEY INFORMANTS:**

**Topic: Socio-Economic Conditions and Retention of Clients in HIV Care and Treatment at Kagadi Hospital**

##### **Interview Questions:**

1. What is your view on the quality of services offered to HIV patients at Kagadi Hospital?
2. Do you think the means of transport used by patients under ART are adequate?

Give reasons for your answer.

3. What is your view on transport costs in the area?
4. Financial challenges are a main source of hindrance to ART patient attendance. Give your view on this statement.
5. Do you think patients receive enough social support in this area? How does this affect their regular ART attendance?
6. What is your view on the retention of patients under HIV care at this health facility?
7. What are the other reasons why patients fail to honor appointments for ART?
8. What can be done to improve ART attendance of patients?

**Thank you for your cooperation.**