

**FACTORS ASSOCIATED WITH HIGH RATE OF ADULT LOST  
TO FOLLOW-UP ON HIV/AIDS CARE AND TREATMENT  
SERVICE IN KYERWA- KAGERA**

**EVALUATION REPORT ON FACTORS ASSOCIATED WITH  
HIGH RATE OF ADULTS LOSS TO FOLLOW-UP CARE AND  
TREATMENT SERVICE IN KYERWA DISTRICT- KAGERA  
TANZANIA**

**By**

**Mutasingwa Florian**

**An Evaluation Thesis Submitted to the School of Public Administration and  
Management in Partial Fulfilment of the Requirements for Award of the Degree  
of Masters of Science in Health Monitoring and Evaluation of Mzumbe  
University**

**2016**

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We the undersigned, certify that we have read and hereby recommend for acceptance by the Mzumbe University, a thesis entitled factors associated with high rate of adult lost to follow up on HIV/AIDS care and treatment services in Kyerwa- Kagera in fulfilment of the requirements for award of the degree of Master of Science in Health Monitoring and Evaluation of Mzumbe University

\_\_\_\_\_  
Major Supervisor

\_\_\_\_\_  
Internal Examiner

\_\_\_\_\_  
External Examiner

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## **DEDICATION**

I devote this work to my spouse Agira Kasenene, my daughter Atugonza Florian and my mama Anaselina Elisa for their moral and material support they offered throughout production of this work. May the Almighty God protect them, bless them, give them prolonged love and wisdom. Amen

## ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti Retroviral Therapy
ARV	Anti Retro Virus
CD4	Immunity Cells
CHMT	Council Health Management Team
CTC	Care and treatment Centre
DAC	District AIDS Coordinator
DMO	District Medical Officer
HIV	Human Immunodeficiency Virus
LTFU	Lost To Follow Up
MDH	Management Development for Health
OI	Opportunistic Infections
PLWH	People Living With HIV
RHMT	Regional Health Management Team
UNAIDS	United Nations Programme on AIDS
UNICEF	United Nation Children's Fund
WHO	World Health Organization
WOMEDA	Women Development Association

## ABSTRACT

The aim of this evaluative study was to determine the factors associated with high rate of adults lost to follow up on HIV/AIDS care and treatment. This cross-sectional study was conducted in Kyerwa-Kagera beginning January up to March 2016 involved 295 clients who were alive and recorded as lost to follow from October, November and December 2015. Semi structured questionnaire with yes and no responses was used for the interview. The questions focused mainly on service accessibility and availability, health system and individual related factors. A Multivariate logistic regression model was used to determine factors that were significantly associated with lost to follow-up. This study revealed that 75.6% of the participants completed standard seven, 99.7% were unemployed, 93.9% had the monthly income ranging between 0 to 5,000 Tanzanian shillings and 77.6% were in stage I and II. The analysis showed that 15.3% were not comfortable with longer time spent waiting for services, and it was evident that 19.3% of participants do not understand benefits of good ART adherence. The factors found to have significant association with patient lost to follow up with (P- value less than 0.05) were approachability of health staff (Odds ratio = 0.00, 95% CI: 2.79 - 0.01), awareness of whether health facility check CD4 (Odds ratio=265.3, 95% CI: 11.02 - 6384), health provider adherence to first in first out principle (Odds ratio = 802.02, 95% CI: 50.71 - 12691), understanding benefits of good adherence (Odds ratio = 20.78, 95% CI: 5.67 - 76.2), use of herbs as alternative medication (Odds ratio=0.01, 95% CI: 0.002- 0.099), and participants that stopped ARV due to religious beliefs ( Odds ratio = 0.00, 95% CI: 7.76 - 0.088). Conclusively after adjusting for other studied factors that were studied and included in the model it was found that factors such as provider approachability, participant's awareness on checking CD4, use of alternative medicine and stopping medication due to faith were more likely to contribute failure of the participant attend care and treatment services as needed. Thus more studies need to be done to determine the magnitude of their effects.

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## **CHAPTER ONE**

### **INTRODUCTION AND STUDY PROBLEM SETTING**

#### **1.1 Introduction**

This chapter introduces the concept of HIV/AIDS lost to follow up on care and treatment services. It starts with a brief background addressing how the problem is portrayed. After this, it goes to the research problem in which it focuses on the magnitude and consequences of increased lost to follow-up. Then it covers the evaluation question and evaluation objectives. Finally, this chapter discusses the justification of this evaluation.

#### **1.2 Background to the problem**

As the 2015 deadline towards the achievement of the sixth millennium development goal has already passed it is estimated that almost 35.3 million people have HIV infections worldwide (UNAIDS, 2013). Various efforts have been to have improved access and ARV to all HIV infected so as to alter HIV/AIDS-related morbidity and mortality since a good number of infected individual are getting highly active ant-retroviral treatment (UNAIDS, 2014). According to the 2012 report by World Health Organization and UNAIDS, it was estimated that 9.7 million people most from low and middle-income countries have received ARVs (UNAIDS, 2013).

Based on the studies done nearly seven million people have managed to leave up to almost their normal life expectancies following the remarkable expansion of access to ART in poor countries especially those living bellow a dollar per day (Babatunde et al., 2015). According to the report initiation of ARV, and improved accessibility of ARV, 30% of lives in sub-Sahara Africa have been saved (UNAIDS, 2013a, 2013b). Furthermore, the countries with low and middle income of which much belong in the southern part of Sahara where there is a high burden of HIV prevalence have benefitted from the ARV- programme coverage (UNAIDS, 2013a; WHO, 2010). Along with enhancing availability of medicines but more efforts have also been made to ensure that all those patients that are eligible to start the lifelong treatment are followed up by taking their records so as to monitor their adherence to medicines which can be reflected through clinical progress and general well-being of clients (Assefa et al., 2010;

FHAPCO, 2010). Individual clients though have not put much attention on drug adherence (Gill & Fox, 2007; Mutasa-Apollo et al, 2014). The evaluation of ARV care and treatment programme in Africa have come across an alarming challenge of increased rate of patients drop out of care (Egger et al., 2011). The observation made is that cumulatively each year there is a good number of clients regarded as lost to follow based on different criteria especially on the number of months the client has not been able to attend clinics for follow-up(Fox & Rosen, 2010; Tassie et al., 2010).

However, it is observed that due to meagre resources and the burden of disease that still need attention the health systems and health care workers who in this regard are referred to as providers set very few of resources to help tracking the missing worse more lost to follow-up is treated as a minor issue the major focus is on clients who are retained on care and have good follow-up as self-initiative. Besides adherence to care and treatment can be assessed over a very short duration, but lifelong patient retention requires a well-set system for a longer period of time in the implementation of the programme.

Attrition is regarded by HIV/AIDS care and treatment programmes as a continuous process of patients drops out of care which occurs over time presenting with a decline in a number of clients enrolled in care and treatment service (WHO, 2013). This drop out of care termed as attrition has various forms of which include (i) patient drop out of care due to death reported as HIV/AIDS-related mortality, (ii) clients lost to follow-up (LTFU) this comprises those patients who are alive but miss scheduled clinic for three or more months consecutively, (iii) patients who remain on care but do not pick up ARV for a certain period of time, (iv) the fourth category includes patients who remain on care but self-transfer from one facility to the other without following the established referral system(Asimwe, Kanyesigye, Bwana, Okello, & Muyindike, 2015). All these contribute to continued increase in losing patients on care and treatment. This study demand was to extract the factors associated high attrition rate in the category of lost to follow-up, stopped medication and self-transfer.

Quitting treatment raises a concern about drug resistance that was likely to arise due to incomplete adherence which further outweighs the much of the expected benefit as per programme implementation plan by ARV care and treatment programmes. HIV infected individuals who already had AIDS clinical presentation but discontinue the use of ART,

and other medicines for the treatment of opportunistic infections were likely to die in a shorter time as compared to those with good adherence and follow-up (WHO, 2013b). as a consequence of sustained patient drop out of care make a serious challenge to the government and other implementing partners which mean there was an inefficient use of very minimal treatment resources (Assefa et al., 2010).

According to WHO the extensive use of highly active ant-retro viral therapy has changed responses of many nations responses toward AIDS and has shown a big positive outcome on health (WHO, 2013a). Based on the review though various programme implementation reports it has been shown that efficient use of ART has reduced the incidence of new HIV-infected cases but also HIV-related deaths (Assefa et al., 2010; Uria et al., 2013). Thus complete monitoring of patients progress may help to determine the success and failures of programme implementation during the evaluation and aid in setting up the intervention in case the gap is identified (Assefa et al., 2010).

Henceforth all HIV/AIDS care and treatment programmes need to keep in mind that for efficient evaluation of the programme performance, monitoring of patients responses especially on adherence to the preset standards is essential. The precaution should be taken that despite initiation of ARV medicines to HIV infected individual there is a possibility for these patients to be lost in the course of continued use of service and that of now it is an upcoming problem (Egger et al., 2011; Muchedzi et al., 2010). In this regard attrition is becoming a significant public health problem (Berheto et al., 2014). However WHO recommends that when assessing the success of ARV programmes attrition should be taken as an important reportable indicator (Gill & Fox, 2007; UNAIDS, 2013a; WHO, 2014).

In East Africa like other countries in sub-Saharan have put much efforts to make sure that eligible HIV clients have significant access to ART, based on the fact that proper adherence and follow-up of HIV/AIDS treatment can prevent infected individuals from developing opportunistic diseases such as tuberculosis, pneumocystis carinii pneumonia, but also prevent other serious illnesses along with altering transmission of infectious diseases such as tuberculosis and HIV to others. Effective use of ARV medicines was associated with improved immunity and hence reduction of morbidity and mortality due to HIV and other disease co-infection.

The new studies suggest that HIV-infected individuals should start treatment so that these benefits are realised as early as possible. (WHO, 2013b). There has been a significant life extension to patients who adhered well to care and treatment instructions (Boulle et al., 2008; Muchedzi et al., 2010). Despite all the efforts the drop out of patients on HIV care and treatment services seems to increase at an alarming rate (Berkley, Mwaringa, & Ndirangu, 2015; Musoke, 2014; WHO, 2011).

As in other countries in sub Sahara desert due to poverty and donor dependent budgets Tanzania continues to experience the consequences of HIV/AIDS and this makes it have a consideration as other major public health problem. Tanzania is one among the countries with obvious efforts to combat new HIV infection but yet it is regarded a country with higher HIV infection rates in the world (UNAIDS, 2013; WHO, 2013) with prevalence of 5.1% in 2012 while the expected estimated prevalence by 2015 was 4.57% (NACP, 2013). According to NACP report number 3 of 2013, it was estimated that about 1.4 million people are living with HIV/AIDS and that deaths associated with HIV infection lead in adults aged 15-49 (NACP, 2013). Being in the third world countries with low income, Tanzania managed to have the greatest number of people on antiretroviral therapy in 2012 where there was a 43% increase in ART coverage (UNAIDS, 2013b). The observed increased coverage has been due to efforts made by the Ministry of Health through the Nation AIDS Control Programme to decentralize HIV/AIDS care and treatment to the lower facility level of health system in Tanzania in order to scale up accessibility of ARV for the needy (Makunde et al., 2012; Somi et al., 2012). It has been noted that reaching December 2012, about 1.14 million people with HIV infection were registered on care and treatment centres both Governmental and Non-Governmental owned health facilities that provide ART of whom 663,911 had started ART under the National Programme (NACP, 2013). The clients who are enrolled in care and treatment has been increasing due to increased access to services while retention on care has become a serious challenge (PEPFAR, 2013; Roura, Busza, & Urassa, 2009; Somi et al., 2012; TACAIDS, 2013).

In Kyerwa district the proportion of clients that have been lost to follow up on HIV/AIDS care and treatment programme has been increasing on yearly basis. For the year 2015, the percentage of clients that were lost to follow-up was 17% as per district routine data report (NACP, 2013).

### **1.3 Problem statement**

Among the HIV-infected individuals it was found that effective utilization of care and treatment services which in this study was regarded as proper adherence and effective service utilization was associated with a reduction of morbidity and mortalities associated with HIV among the infected individuals. The gradual decline in number of clients who properly follow the HIV care and treatment services, which seems to increase, poses a challenge towards the efforts that have been set to save lives of the infected people. The percentage of clients who fail to attend care and treatment service as a programme in Kyerwa has also been noted to increase significantly. The current status of infected clients that have been noted as lost to follow-up care is approximately 26% among all HIV-infected client that were enrolled in care and treatment national wide (NACP, 2013). Kyerwa District is approximated to have about 17% of all clients who were enrolled in HIV/AIDS care and treatment services have dropped out. This study to determine the factors associated with high rate of adult drop out of care was needed so as to provide support towards understanding the cause and set the ground to arrest the LTFU in patients enrolled in care and treatment but also initiated ART.

### **1.4 Significance of evaluation**

Morbidities and mortalities resulting from improper adherence to HIV/AIDS care and treatment instructions are preventable (Boulle et al., 2008). Without regulated and proper patient tracking system of patients enrolled in care and already started using ART, lost to follow up patients are likely to lead to emerging of drug resistance and hence treatment failure. This predicted threat is likely to be a setback that may result in a reduction of treatment options alongside with the transmission of drug-resistant HIV viral strains. Effective attendance as well as follow up on HIV care and treatments enables early detection and diagnosis of opportunistic infections and their treatment.

Moreover, it is very important and crucial to understanding as to why the trend of lost to follow-up among HIV-infected people continues to rise up, since retention of people on ART and ensuring adherence to treatment are essential determinants for victorious long-standing programme outcomes. Therefore, this study is important as it intends to extract from the clients what could be the reasons or factors associated with high rate of adults lost to follow up on care and treatment service. This programme evaluation, however, would further enable the district HIV/AIDS management team and MDH a non-governmental organization to know which factors are interfering with programme performance and hence be able to sort out these drawbacks, constraining the efforts made to improve the life of people living with HIV in Kyerwa district. Last but not least the study findings also would enable the programme implementing partners to know where to intervene and generally know what could be the possible hindrances toward achievement of the project's goal. However the findings intended to add to a body of knowledge about factors contributing to increasing rate of adults failing to attend HIV/AIDS care and treatment clinics accordingly thence enable to set up an intervention for improvement.

## **CHAPTER TWO**

### **2.0 Description care and treatment programme**

The care and treatment programme was set up and supported by MDH so as to enable availability and accessibility of care and treatment services in Kyerwa. This went hand in hand with improving the quality of service delivery through building capacity of service providers, improving the infrastructures, strengthening laboratory services but also ensuring availability of ARV to all eligible clients. MDH conducted training to health providers working in CTC on the pre ART about client adherence to care and treatment services. The programme also strengthened laboratories by supplying them with CD4 machines, reagents. Also the chain supply of ARVs was strengthened such that no clients eligible to use ARV missed the medicines

Thus after completing all the activities the challenge of continuous increase of the number of clients who are reported as lost to follow up was realised through reviewing the monthly and quarterly programme reports. Thus this evaluation intended to establish the factors that were associated with LTFU.

### **2.1 Programme stakeholders**

This programme involved Kyerwa District Council and all the facilities that are providing HIV/AIDS services. These health facilities were of major concern as it the first point that clients are captured and receive services. Also MDH as the NGO highly involved in care and treatment services, and with others HIV/AIDS interventions was a key stakeholder of the programme

Other stakeholders included are the outreach partners such as WOMED (Women Development Association) and other community social organisation dealing with HIV services in the community.

Important stake holders were the PLWH as these are key drivers and observable outcomes of programme performance. Without these clients the programme would not exist and they are the primary beneficiaries of the programme.

## **2.2 HIV /AIDS care and treatment programme implementation programme objectives**

The specific objectives of this programme were:

- i. To improve accessibility and quality of care and treatment
- ii. To increase adherence to ARV treatment
- iii. To improve care and support for people living with HIV enrolled in care
- iv. To strengthen capacity of health care providers working in care and treatment centres.

## **2.3 Scope of evaluation**

This evaluative study intended to assess factors that were associated with increased rate of adults lost to follow up on HIV/AIDS care and treatment services in Kyerwa district at various health facilities. Particularly the evaluation focused on system related factors, service provider factors and service recipient related factors based on the predetermined activities of HIV/AIDS care and treatment project. The sample population selected for this study were limited to clients enrolled in HIV/AIDS care and treatment services in Kyerwa. As a consequence the ability to generalize the results to the whole population of HIV-infected clients in Kyerwa district and beyond its borders is limited.

The study participants, however, were sampled from the population that attends HIV/AIDS care and treatment service sessions that have not been able to attend for care and treatment for the months of October, November and December 2015 in Kyerwa but still alive. Hence the findings can generalize to other lost to follow up clients in other districts of Tanzania.

## **2.4 Programme Logic Model**

### **2.4.1 Overview**

Despite all efforts made by the programme to improve the quality of HIV/AIDS care and treatment programme through improving the quality of care the number of clients lost to follow-up is increasing at a high rate. This was identified through routine data that were collected routinely from the CTC sites. This evaluation was set to assess what could be the factors associated with lost to follow-up of clients. It assessed the input and process on how the programme was being implemented.

The inputs included the availability of supplies such as availability of ARV, laboratory reagents, CD4 count machine and quality of providers. The process evaluation involved assessment of provider performance and contribution to LTFU, accessibility and availability of services but also the recipient related factors that high rate of adult lost to follow-up.

Much of the assessment was based on the programme logic model as it shows details of how the programme was to be implemented as shown in Table 2.1.

**Table 2.1 Programme logic model**

Super goal: To mitigate the socio-economic and health impact of HIV/AIDS in society			
Goal: Increase access and availability of ARV to eligible people living with HIV/AIDS			
	Verifiable indicator	Means of verification	Risks and assumptions
Outcome: To achieve access to high-quality comprehensive treatment, care and support in an environment that supports adherence and change the behaviour of adults lost to follow up on care.	<ul style="list-style-type: none"> <li>- % of adult with advanced HIV infection who are receiving antiretroviral combination therapy</li> <li>- % of adults attending care and treatment clinics regularly each month</li> <li>- % of adults expressing good ART adherence and follow up on care and treatment</li> <li>- % of adults alive and but have not attended care and treatment clinics for past three consecutive months</li> </ul>	<ul style="list-style-type: none"> <li>- Monthly ART registers</li> <li>- Monthly PLWHA attendance report</li> <li>- Quarterly report</li> <li>- Adherence Counsellors/ Social Workers reports</li> <li>- Monthly treatment site reports to the district surveillance officers</li> </ul>	<ul style="list-style-type: none"> <li>- Sustained availability of ARV</li> <li>- Financial stability to enable travelling of patients to health facility</li> <li>- Implementing partners and NGOs to remain engaged</li> </ul>
<p>Output:</p> <ul style="list-style-type: none"> <li>-Improved access to and quality of ARV treatment.</li> <li>-Increased adherence to treatment and care.</li> <li>- Improved access and use of Home Based Care.</li> <li>-Improved the diagnostic capacity of the laboratory services.</li> <li>-Training programmes conducted</li> <li>-Change in providers attitude</li> </ul>	<p>Verifiable indicators:</p> <ul style="list-style-type: none"> <li>- % of adults with advanced HIV infection who are receiving antiretroviral therapy</li> <li>- % PLWH on ARVs reporting at least 95% adherence</li> <li>- Number of PLWHA receiving home-based care within the last 12 months</li> <li>- Number of patients having CD4 tests done</li> <li>-Number of persons trained in the service area and programme</li> </ul>	<p>Means of verification:</p> <ul style="list-style-type: none"> <li>- Monthly treatment site reports to the district surveillance officers</li> <li>- Adherence Counsellors/ Social Workers reports</li> <li>- Quarterly district technical reports by the district HIV Coordinators</li> <li>- Quarterly laboratory tests and results by the district laboratory Coordinator.</li> <li>- Quarterly technical reports by the district HIV/AIDS Coordinator.</li> </ul>	<p>Risks and assumptions</p> <ul style="list-style-type: none"> <li>- Availability of medicines</li> <li>- Willingness of patients to follow-up medicines</li> <li>- Commitment of NGOs to support the programme</li> </ul>
<p>Activities</p> <ul style="list-style-type: none"> <li>- Increase the number of sites at which treatment is available by involving all Primary Care Staff in Treatment and maintaining the current Treatment Centres as Specialist referral sites.</li> <li>- Retrain Clinic Staff in updated HIV Management Protocol on an annual basis</li> <li>- Improve access to CD4 testing.</li> <li>- Conduct appropriate follow-up of patients</li> </ul>			

- Conduct quality assurance audits at all levels of service.
- Develop and implement an information tracking system that facilitates effective management of appointments and medication.
- Improve supply management structure for ARVs.
- Review TOR of adherence counsellors to include counselling for HIV testing as well as adherence counselling on a wider scale, in the treatment centres
- Development of a structured adherence protocol for pre-ARV treatment.
- Strengthen adherence programme by the involvement of all members of the treatment team.
- Provide training in adherence to all members of treatment team
- Development of treatment support groups.
- Simplify regime by increased availability of fixed combination medicines
- Collaborate with NGOs and other relevant agencies that can provide financial and social support (for meals, transportation, school fees) and income generating assistance to PLWH
- Develop a registry of home-based caregivers and agencies to provide these services and disseminate this information
- Provide training to caregivers in Home Based Care.
- Involve family members and other support groups such as Churches in the training of home-based care.
- Improve the capacity of the laboratory to carry out CD4, Viral Loads, and other supportive investigation.
- To develop standard short courses for HIV case managements, PMTCT, Adherence, Infection Control and Counselling for health care workers.
- Conduct training for health care worker
- Conduct audits to ensure standard and quality of care.

**Input:**

- Human resource ( Project coordinators, clinical staff, trainers, volunteers, monitoring and evaluation team, Supportive NGOs
- Funds from Central government, Donors, Community-based organisations, religious organizations
- Training materials and guidelines, policies and regulations
- Supply of ARV, Laboratory reagents, CD4- machines.

## **CHAPTER THREE**

### **LITERATURE REVIEW**

#### **3.0 Introduction**

This chapter gives the narrations and theoretical support of this study as to why it was undertaken. Also it contains information and findings from other similar studies. And this chapter explains what other scholars did and what the identified findings were. The study also addresses gaps that were identified from other journals and articles that are published and how they are related with the problem studied. Furthermore the link between various objectives in association with the study topic are conceptualised with in this chapter.

#### **3.1 Theoretical Literature review**

There have been notable success and improvement of ART scale-up and coverage that was well documented from the global perspective, contrary to attrition information which is a major programmatic challenge no adequate documentation that gives satisfactory details about lost to follow-up (Molfino et al., 2014; WHO, 2010). As far as attrition is concerned from a definition that; it is a combination of patients lost to follow-up on care, patients who die due to HIV-related diseases, but also those clients that deliberately decide not to pick up ARV drug (FHAPCO, 2010; Gupta et al., 2014). From the time the roll out of wide ARV coverage and improved access to care and treatment the programme has managed to retain almost 60.5% of participants on care(Geng et al., 2010). Among the major causes of the patient drop out of care lost to follow-up care carries a big percentage of those patients being classified as in attrition (Rosen, Fox & Gill, 2007a). On that note, it is essential that patient retention on care makes a useful measure for programme performance and effectiveness.

This group of patients classified as lost to follow-up have been categorised in several subgroups based on how individuals explain the current practice to obtain the ARV medicines. From that point there are patients who are grouped as lost to follow-up and from their initial CTC they are regarded as they are not using medicines and have stopped attending clinics while these same clients have shifted from one CTC to

the other and registered with different name or sometimes with the same names without following proper channels for transfer (WHO, 2014). These patients who self-transfer have genuine reasons to transfer such when they were initiated on care and treatment the facility they used to attend is far away since there is a new nearby health facility, transport cost to continue attending the furthest CTC site but also they are avoiding stigmatization by attending a new site where they are not known.(Egger et al., 2011). For site managers the universal monthly reporting that contains cross-sectional patient report it is essential to review those reports that contain the records of patient in total but also those who have been lost to follow-up in a particular month, his is helpful to to keep tracking the progress of these patients (Agu et al., 2012). These reports contain also other parameters such as patients on the various regimen, patients tested CD4, viral load and out but also records of patient outcome such as in care, transferred out lost to follow-up and died (Boulle et al., 2008). Apparently, it is reasonable to assess mortality among all patients who started ART in particular cohort so as to know who are still alive and on care or have been lost to follow-up (Egger et al., 2011). It is not well known to what degree in the future the increasing lost to follow up will result in it could be increased deaths, existence of resistant viral strains due to multiple repeated treatment interruptions (Boulle et al., 2008). It has almost been a common or similar finding in collaborative HIV/AIDS programme data review from Africa, Asia, and South America the common finding was that lost to follow up ranges from 21% to 35% of all patients enrolled on care and treatment services in different parts of the world (Geng et al., 2010; Uria et al., 2013). The trend of lost to follow-up was seen to have almost a similar trend that patients begin to drop out of care even after six months of ART initiation.(Shaweno, 2015)

### **3.2 Empirical Literature Review**

A review of multiple published journals about tracing patients who were regarded as lost to follow-up found that majority of these patients had a high mortality rate in comparison to those who remained in care (Egger et al., 2011; Mutasa-Apollo et al., 2014).

Further, systematic review indicated that approximately 40.5% of the clients living with HIV but dropped out of care had been deceased, 33% other had self-transferred to other facilities which means they were accessing care and treatment elsewhere (Rosen et al., 2007a). Furthermore, the currently published reports from South Africa state that 13% of the people have silently transferred to other facilities within few years post drug initiation (Mugglin et al., 2014; SPRAGUE, 2009). These findings give provide a scenario to explain on how difficult it is to know the clinical progress of patients even those followed up in particular cohort hence there is need to have well-established system that will aid in tracking all clients where they receive services especially those with sustained habit of self-transfer (UNAIDS, 2013b; WHO, 2013a).

Some of the clients who make silent self-transfer due to the newly established care and treatment clinics but also other have changed from initial CTC site to avoid stigma hence go to a new convenient clinic (Egger et al., 2011; Makunde et al., 2012). Also, attrition rates among HIV-infected patients vary based on the facility level where they were initially, but also the availability of extra services such provision of medicines for the provision of opportunistic infection, the supply of nutrition supplements (Molfino et al., 2014; Shaweno, 2015).

Service providers have a major role to play so as to make sure patients adhere to care and treatment services. Through the provision of service like psychosocial support and counselling sessions that educate the clients regarding proper adherence to care and treatment (Lamb et al., 2014; Muchedzi et al., 2010). Prior to initiation of care and treatment services but also during the continuation of life-long services, there are sessions that have to make sure the people living with HIV understand the importance of adherence (MoHSW & NACP, 2012).

The quality of patient-provider interactions is of great importance since, the documents review has shown that some of the HIV-infected individuals need the environment that is sympathetic, hence whenever such environment is not made available meaning lack of hospitable provider-client relationship may lead to worse patient adherence thus drop out of care (Watt et al., 2010).

Therefore on the job training, mentoring and supportive supervision may aid to enable the establishment of good provider-client relationship hence retentions that are according to the studies (Reda & Biadgilign, 2012). Due to a shortage of health care staff but furthermore due to special HIV care and treatment clinics that need additional health staff clients may be by the irregularity of health care service providers patients are not effectively attended (Muchedzi et al., 2010; Mugglin et al., 2014). Furthermore dissatisfaction with response made by health care providers on the concerns about side effects of medicines, handling of defaulters and other care and treatments queries results into dissatisfaction that lead to PLHIV not going back to clinics (Bond, & Merten, 2012).

Some others have cited individual personal behaviours and attitudes such as being not being friendly, perceived rudeness of some clinic staff, the unsympathizing behaviour and lack of dignity frustrated and persuaded people living with HIV from seeking care (Muture et al., 2011).

People living with HIV who access care and treatment are facing several challenges such as long waiting time for care during care, uncertainty of accessing important services such control cd4 check up, viral load testing and other HIV/AIDS-related services (Chi et al., 2009; Muchedzi et al., 2010; Mugglin et al., 2014). Recurrent episodes of inconsistent availability of ARV medicines at the clinics on scheduled clinic days may discourage continued visiting the clinics as consequence patients drop out of follow-up (Muture et al., 2011).

The point of where the client primarily was accessing care such from higher level healthcare facilities and overcrowding at the ART clinics may be associated with lost to follow-up (Lamb et al., 2014; Mutasa-Apollo et al., 2014). Adoption of extra supportive services such food supplementation, Co-trimoxazole availability as a strategy seems to improve patient retention (Mugglin et al., 2014). To improve the accessibility of ARV and reduce the annoying overcrowded clinics by accrediting remote and peripheral health facilities but also running outreach services so that ART initiation and possible drug refilling would narrow the growing gap of patient lost to follow-up (Boyles et al., 2011; NACP, 2013).

Perceived health system issues such as long queues during the clinic, long time of travel are considered to contribute on patient drop out on care treatment (Perriëns et al., 2013; van der Kop et al., 2014). A bureaucratic health system with the laborious registration process lost referral letter and high hospital fees (Adeneye, 2006; Ferguson, 2011; Muchedzi et al., 2010). Other problems that are associated with the health system include the weak pre-ART referral systems and poor quality services (Obermeyer et al., 2013). To stress the matter it is that health system barriers such as complexities but also bureaucracy that have to be followed are associated with interference in regular but also on time dispensing of medicines to patients, may result in poor adherence and hence lost to follow-up (Reda & Biadgilign, 2012). Studies have found out that majority of clinics have very few and limited number of clinicians providing service hence patient may visit the clinic and is being attended by the same provider such that there is no opportunity given to clients to meet a clinician that could open the room to express their progress this has been noted to have high risk of attrition (Apollo et al., 2014).

The other reason for the high LTFU in case a patient is referred to health facilities such as the regional referral health facility where there many patients and the chances that an HIV client will be seen by several people is high as compared to the primary care and treatment clinic which is situated strategically to attend HIV/AIDS patients only (Makunde et al., 2012). A study done by (W. Roura et al., 2009) found that referral hospital have had a bad reputation such that client referred to such areas such when a client is referred may not attend and hence get lost along the course of treatment and referral point .

Service accessibility is influenced by individual income hence inadequate financial stability may result into the drop out on following treatment (Muchedzi et al., 2010; van der Kop et al., 2014). Even if HIV/AIDS care and treatment are for free there are indirect costs of care in accessing ART such as fee for transportation, costs for buying food and at times fees for managing some opportunistic infections are not negligible for a client in continuing and sustained care (Mohammed & Haile, 2014; Mukherjee, 2006; Tsague et al., 2008).

A similar finding was noted by (Mugglin et al., 2014) such that people with low socioeconomic status are likely to drop out of care and finally deteriorate to death. This situation happens even to clients that have been on care and treatment for quite a long time (Mberi et al., 2015).

Patients that have isolated themselves from other community members, but more specific those that are not involved in treatment support groups are considered as being at much more risk of lost to follow-up (Brinkhof, 2009). Failure to disclose the serostatus even to family member among HIV-infected individuals is considered as warning indicator towards patient loss to follow-up of care and medicines adherence among patients (Reda & Biadgilign, 2012a). When making a comparison between two categories of patients meaning those who disclosed their status and those who never disclosed the information to any family member the latter have a higher risk of lost to follow-up studies have revealed that (Mayanja et al., 2013; Shaweno., 2015).

Inadequate knowledge on the need for treatment compliance and adherence to care and treatment instruction, together with inadequate knowledge about HIV is considered the most frequent reason attributed to attrition (Lamb et al., 2014; Musheke et al., 2012; van der Kop et al., 2014). In considering gender variation it was observed that male gender was independently associated with higher rate of drop out (Ekouevi et al., 2010).

Some literature document that due to side effects of the medicines to some patients intentionally do not take their pills (Reda & Biadgilign, 2012; Watt et al., 2010) with that they see no reason to continue attending care and treatment clinics. Lost to follow-up as one of the factors leading to high attrition rate may also be related to patient who unofficially transfer to other facilities such as nearby primary health facilities were they could access a better quality of medical care and follow-up (van der Kop et al., 2014).

Health seeking behaviour such as rely on alternative services, herbalist dependency, some of the patients stopped attending the HIV care and treatment services due to religious influence (Miller et al., 2010; Musheke et al., 2012). There are patients who believe that HIV can be cured thru prayers but also others do not believe in modern medicine (Mucedzi et al., 2010).

Furthermore spiritual believe made patient to believe that were “served” and cured of the HIV/AIDS, others changed ARV into local herbs (Bezabhe et al., 2014).

Some studies have found out that following the initiation of ARV some of the patients gain immunity and hence their general health condition improves, to the extent that one feels as well and cured now this wellbeing may be used as a reason why they stopped attending care and treatment (Boyles et al., 2011; Muture et al., 2011).

Some of the studies have been able to come up with possible reasons that some clients use herbal medication as an alternative to ARVs, another claim that they have been healed through their religious beliefs hence saw no need to continue attending for care and treatment clinics (Reda & Biadgilign, 2012). The same study found out that due to patients fear of drug side effects and far away distance to a health facility were directly associated with poor retention on care and treatment.

Others have gone further to say that they lack trust in the services and information given to them about HIV but also still mentioned distance to treatment clinics, lack transport fare and lack of social support contributes to the gradual failure to follow up services (Agozie, 2012; Musoke, 2014; Tweya et al., 2013; Assefa et al., 2010; Wasti et al., 2012).

The loss to the programme is noted to be significantly high in men with poor immunity referring that client with very low CD4 count (McGuire et al., 2013). The patients such as those in WHO clinical stage IV were mostly linked with increased risk of attrition (Mutasa et al., 2014; Baggaley, 2013). People living with HIV/AIDS and have been involved in formulating treatment support groups are more likely to continue following up treatment than those who are never a member of treatment support groups (Adeneye, 2006; Muchedzi et al., 2010).

Sustainability of clients on care and treatment services depends on multiple interlinked factors. This goes to a level of economic, social, health system and personal health seeking behaviour.

Individual income and type of employment have been related to good adherence, which means there are contracts that fully bind workers to the extent that they are not given a chance to leave job sites to in order to attend monthly clinics (Musheke et al., 2012).

It is a challenge while studies suggest that all HIV-infected individuals qualify to start using ARV it should be taken in mind that retaining these asymptomatic patients on routine follow up on care difficult to be foreseen by the implementing partners (Perriens et al., 2013). Poor nutrition to the HIV-infected people also adds to the weakening of the already immune compromised individuals hence more at risk of opportunistic infections such as tuberculosis (Molfinio et al., 2014). The individuals with advanced stage are at times bedridden hence without the family support they are not able to attend clinics hence regarded as lost to follow-up. Thus early diagnosis and management of the clients before he/she goes to advanced stages may reduce attrition and mortality (Somi et al., 2012). When the clients are managed at early stages is likely to experience noticeable physical wellbeing and hence reduce the risks of attrition from the programme as it possible to gain hope with obvious physical recovery (Roura et al., 2009).

Patient retention in care and treatment not only beneficial in reducing morbidity and mortality of the infected individuals but also prevention of transmission (Berheto et al., 2014). Most of the clients in Africa and diagnosed while they have developed clinical conditions thus without the availability of ARV these clients would have died of AIDS-related illnesses (Ekouevi et al., 2010). Thus patients retained on care and treatment is considered as a life saved as the majority of those who drop out care progress to severe clinical condition and hence die within a short time if not returned on care.

### **3.3 Conceptual frame work**

As derived from the reviewed studies, it has been realized that providers, health system, service availability and client related factors have a role to play towards clients, satisfaction and hence maximize their life-long follow up of medicines.

These identified features together are thought to work together have effect towards influencing drop out of HIV/AIDS care and treatment programme among the clients. Thus, this study intended to determine among these factors what hinders programme performance and hence a continued increase in number of clients who are lost to follow up care and treatment.

## **CHAPTER FOUR**

### **EVALUATION QUESTIONS AND OBJECTIVES**

#### **4.1 Evaluation question**

What are the factors associated with high rate of adults lost to follow up on HIV/AIDS care and treatment programme in Kyerwa district?

##### **4.1.1 Specific evaluation questions**

- i. What are service provider factors related with a high rate of adults lost to follow up on HIV/AIDS care and treatment programme in Kyerwa district?
- ii. What are service accessibility and availability factors associated with high rate of adults lost to follow up on HIV/AIDS care and treatment programme in Kyerwa district?
- iii. What are service provision system factors related with a high rate of adults lost to follow up on HIV/AIDS care and treatment programme in Kyerwa district?
- iv. What are service recipient factors associated with high rate of adults lost to follow up on HIV/AIDS care and treatment programme in Kyerwa district?

#### **4.2 Main evaluation objective**

Thus the main objective of this study was to determine the factors associated with high rate of adults lost to follow up on HIV/AIDS care and treatment service in Kyerwa district from service recipients.

##### **4.2.1 Specific evaluation objectives**

- i. To determine service provider related factors for high rate of adults lost to follow up on HIV/AIDS care and treatment service in Kyerwa.
- ii. To determine service accessibility and availability factors associated with high rate of adults lost to follow up on HIV/AIDS care and treatment service in Kyerwa district.

- iii. To assess service provision system factors related with a high rate of adults lost to follow up on HIV/AIDS care and treatment service in Kyerwa district.
- iv. To establish service recipient related factors for high rate for adult lost to follow up on HIV/AIDS care and treatment services in Kyerwa district.

## **CHAPTER FIVE**

### **EVALUATION METHODOLOGY**

#### **5.0 Overview**

This chapter presents the procedure of the evaluation methodology that was used to determine the factors that were related with adult lost to follow up on care and treatment service and the chapter further describes the methods used to realize the findings of the study.

#### **5.1 Study area**

The present study was conducted in villages and hamlets of Kyerwa district in collaboration with Isingiro hospital, Mulongo, and Nkwenda health centres. Also, Kaisho dispensary was involved as it provides HIV/AIDS care and treatment services.

#### **5.2 Evaluation Period**

The period of evaluation was of three months targeting clients who are reported as lost to follow-up during the months of October, November and December 2015. Data were collected in January and February 2016.

#### **5.3 Evaluation Approach**

The present quantitative study design involved the use of the pre-coded questionnaire that was semi-structured. The open-ended question responses were coded after data collection after looking at the pattern of the responses obtained from respondents.

#### **5.4 Evaluation design**

The study used a cross-sectional study design and data were collected from adults living with HIV but reported as lost to follow up on care and treatment.

## **5.5 Variables**

### **5.5.1 Dependent variable**

The dependent variable for this study was a failure of attendance at any care and treatment centre in three months prior to the study.

### **5.5.2 Independent variables**

Independent variables for analysis included background variables like age, sex, marital status, education level, occupation, months passed since last attended clinic, HIV clinical stage and the client's last CD4 count. Variables for service provider related factors such as staff availability attitude friendliness, responsiveness, approachability, confidentiality and their commitment to the care and treatment service. Factors related to service accessibility and availability through variables of ARV medicines availability, CD4 testing availability, lessons provided before ARV initiation, the opportunity to choose desired health provider and distance to a health facility were assessed. Furthermore, service provision system related factors such as long waiting time, schedules of care and treatment clinics, the bureaucracy of health system and opportunity to choose desired health providers. Finally, the client related factors that were related with high adult drop out on care and treatment service thru variables of individual income, health seeking behaviour, stigma and collaboration with other treatment supporters, medicines side effects, knowledge on proper adherence and whether an individual is a member of any treatment support group.

## **5.7 Populations and sampling**

### **5.7.1 Target Population**

The target population involved in this study were all people living with HIV/AIDS, who were already registered for care and treatment to all CTC but reported as lost to follow up in Kyerwa District.

### **5.7.2 Source Population**

The participants of this study were selected among the clients that did not attend care and treatment services at their initial clinic where they were registered for care and

treatment from the months of October, November and December 2015 Kyerwa District.

### **5.7.3 Study Population**

The study population included all clients who were recorded in the lost to follow up tracking register from four selected health facilities in Kyerwa District.

### **5.7.4 Study units and Sampling units**

The study involved individuals with HIV infection who were lost to follow up on HIV care and treatment clinics but have not attended for the past three months.

### **5.7.5 Sample size**

A total sample of 295 was calculated using single proportion formula as follows;

p: The percentage of the of patients attrition among HIV clients enrolled on care and treatment services is 26% in sub-Saharan Africa (Molfinio et al., 2014).

q: Percentage of clients retained on care (100-p)=74%

d: The precision of the estimate =5%.

Z $\alpha$  [Z alpha]: The value of z from the probability tables.1.96 at 95% confidence interval.

The sample size was calculated as  $N = (Z\alpha)^2 \times (pq)/d^2$

$$N = 1.96^2 \times (0.26 \times 0.74) / 0.05^2$$

$$N = 295.65 \sim 295 \text{ people}$$

The study involved 295 people.

### **5.7.6 Sampling Procedures**

The list of clients who were recorded as lost to follow up was obtained from four selected health facilities that is Isingiro hospital Nkwenda, Mulongo and Kamuli health centres. From the list of lost to follow up clients at each facility a systematic sampling was done where clients registered with a number without decimal places were selected and included in this study.

### **5.7.7 Inclusion and Exclusion criteria**

Inclusion criteria were only PLWH reported as lost to follow-up at the selected care and treatment centres that have not attended their initial care and treatment clinics for the months of October, November and December 2015.

## **5.8 Data collection**

The present study used semi-structured questionnaire. The questions focused on extracting the provider related factors; service availability and accessibility factors, system related factors and recipient related factors from among the lost to follow up clients that led them not returning for follow-up of care and treatment services.

### **5.8.1 Development of data collection tools**

The questionnaire for data collection was prepared and thereafter, pre-tested and improved accordingly at St. Kizito hospital at Mikumi centre using 5 clients who were visited at their homes.

### **5.8.2 Data Collectors**

The data collection was performed by the researcher from January 2016 to end of February 2016 during work hours from 8.00am through 6.00pm. Data were collected from adult people living with HIV who had not attended care and treatment clinics for follow-up for the months of October, November and December 2015 based on the reports obtained from the randomly selected health facilities.

### **5.8.3 Data collection field work**

The overall data collection activity was done by the principal investigator of the study assisted by the Home based care providers to who assisted the researcher in visiting the identified clients. All completed questionnaire were examined every day after data collection for completeness and consistency.

## **5.9 Data management and analysis**

### **5.9.1 Data entry**

Data were first coded from text into numerical and entered into excel sheet by double entrants.

### **5.9.2 Data Cleaning**

Data cleaning using excel computer programme to remove errors in terms of accuracy and inconsistency of responses was done.

### **5.9.3 Data analysis**

Descriptive statistics was done to characterize the data by percentage and frequency. To identify independent predictors of lost to follow-up Chi-square test of independence was done to see the associations between dependent and independent variables. The variables related to the study objectives, including age, sex, marital status education level, employment status, months passed since last clinic, CD4 count from CTC-1cards and WHO clinical stage, staff friendliness, staff communication, readily availability of health staff, harsh language, staff response, staff approachable, confidential information, treatment reliable, commitment to work, time taken to listen patients and patient leaving clinic unattended. Other variable that were used for analysis included checking CD4 count, missed ARV, means of transport, time taken to facility, comfortable with waiting time for care, being happy with scheduled clinic days, flexible health staff, comfortable with bureaucracy, lessons attended prior to ART initiation, benefits of good ARV adherence, income, use of herbal medications, ARV side effects, healed by faith, treatment support awareness, member of treatment support group, individual reasons not attending CTC and the experience from observation of others.

Data analysis was done by using SPSS version 20 was used for univariate and bivariate analysis and the frequency distribution for each variable was determined, also Pearson chi-Square and Fischer's exact test were done to determine the association between variables.

Cross tabulation of variables was done and confidence interval with a p-value of 0.05 was used to determine the significance of the association between variables in this study.

#### **5.10 Ethical considerations**

Ethical clearance was obtained from Mzumbe University as it is mandated to read the research proposal and deliberate the quality of research including ethical considerations through the school of public administration and management (SOPAM). The permission to conduct the study in Kyerwa district was offered after the district authority involving the DMO officer had approved for execution of the study.

#### **5.11 Evaluation report dissemination plan**

These evaluation findings will be submitted to the university in report form but also the copy of the report shall be submitted to Kyerwa district medical officer. Furthermore, presentations shall be made to the regional HIV/AIDS stakeholders meeting and at the national level if opportunities are obtained. Publication of the report in peer review journal will also be done.

#### **5.12 Study Limitations**

No limitations encountered during data collection as the researcher developed the tool and used to collect data but also prior to using the questionnaire it was pretested to similar clients and the difficulties encountered during piloting were resolved.

#### **5.13 Challenges encountered**

Data collection was conducted in the countryside bordering three countries of Uganda, Rwanda and Burundi where some patients who attend the clinics are from those countries that made it hard to reach them but also other clients who were selected for study had returned to their home countries as false emigrants. Also, other participants have already shifted from Kyerwa district to other districts and regions of Tanzania. Due to such issues sampling was done several times so as to obtain new clients to reach the predetermined sample size. However, the study has generated new insights about patient-provider interactions, the lack of treatment support group

which contributes to the body of knowledge on factors influencing patient retention in ART care.

## **CHAPTER SIX**

### **EVALUATION FINDINGS**

#### **6.0 Over view**

This chapter presents sets of information as obtained from the collected data and analysed based on the objectives of the study.

#### **6.1 Social-demographic characteristics**

Table 6.1 summarizes the socio-demographic characteristics of the study participants. A total of 295 clients who are lost to follow-up on HIV care and treatment services from Kyerwa district with 100% response rate were recruited into the study. The study involved 190 (64.4%) coming from Nkwenda health centre, 76 (25.8%) from Isingiro hospital, 25(8.5%) from Murongo health centre and 4(1.4%) from Kaisho dispensary. The study managed to capture the predetermined sample size of 295 people after repeated random sampling as some of those who were sampled initially were among the people who were returned to neighbouring countries as illegal emigrants.

In this study majority 158 (53.6%) of participants were aged between 31-40 years, of these 188 (63.7%) were married, with 100% of participants unemployed in the formal sectors other details socio demographic features are summarised in Table 6.1.

**Table 6.1: Social demographic characteristics of study participants (N=295)**

<b>Variables</b>	<b>Frequency</b>	<b>Percent</b>
<b>Age categorised</b>		
11-20 years	4	1.4
21-30 years	83	28.1
31-40 years	158	53.6
41-50 years	34	11.5
51-60 years	16	5.4
<b>Sex</b>		
Female	150	50.8
Male	145	49.2
<b>Marital status</b>		
Single	36	12.2
Married	188	63.7
Widow/widower	57	19.3
Divorced	14	4.7
<b>Education level</b>		
Not completed STD VII	65	22
Completed STD VII	223	75.6
Form four leaver	7	2.4
<b>Employment status</b>		
No	295	100
Yes	0	0
<b>Categorized participants average monthly income</b>		
0-5000	277	93.9
5001-10000	16	5.4
10001-15000	2	0.7

## **6.2 Clinical characteristics of study participants**

Regarding the WHO HIV/AIDS clinical staging of HIV infected individuals majority of clients based on the readings from the CTC1 cards were stage 1 and 2 with 104 (35.3%) and 125 (42.4%) respectively.

**Table 6.2: Clinical characteristics of people living with HIV/AIDS but lost to follow up on care and treatment in Kyerwa District, Kagera**

Variables	Frequency	Percentage
<b>Clients WHO clinical HIV stage</b>		
Stage 1and2	229	77.6
Stage 3&4	66	22.4
<b>Categorised CD4 counts</b>		
0-100	2	0.7
101-200	128	43.4
201-300	121	41
301-400	36	12.2
401-500	8	2.7
<b>CD4 Count re-categorized</b>		
≤ 350	270	91.5
>350	25	8.5

### 6.3 Service provider related factors

Table 6.3 shows the features assessed from study participants as regards to what could be the contribution of service providers towards sustained increase in number of clients who are lost to follow up (N=295). Majority of the clients 292 (99%) declared that the health information about HIV that are given to them were reliable but also about 2.7% said health providers had harsh language.

**Table 6.3: Service provider, health system related factors people living with HIV/AIDS lost to follow up on care and treatment.**

Variables	Frequency	Percentage
<b>Health care staffs friendliness at facilities</b>		
No	33	11.2
Yes	262	88.8
<b>Enjoying the way health staffs communicate</b>		
No	49	16.6
Yes	246	83.4
<b>Use of harsh language by health staffs when attending clients</b>		
No	287	97.3
Yes	8	2.7
<b>Happy with the way the health staffs respond to requests</b>		
No	7	2.4
Yes	288	97.6
<b>Easy to approach the health care provider</b>		
No	17	5.8
Yes	278	94.2

#### 6.4 Health system related factors

According to 289 (98%) of participants, it was found that health providers were readily available at the CTC during the scheduled visits, 97.3% of participants have never missed ARV, never the less it was stated by 97.6% of participants that they are never given opportunity to choose a clinician even though 98.3% recognised the health providers commitment to work. Further details on the information obtained when assessing the providers related factors on failure to attend CTC are summarised in table 6.4

**Table 6.4: Health system related factors**

Variable	Frequency	Percentage
<b>Health staff providing care and treatment services ready availability</b>		
No	6	2
Yes	289	98
<b>Ever gone to a health facility and missed ARV</b>		
No	287	97.3
Yes	8	2.7
<b>Ever heard in streets the confidential information revealed to CTC health provider</b>		
No	253	85.8
Yes	42	14.2
<b>Health information about HIV/AIDS reliable</b>		
No	3	1
Yes	292	99
<b>Health service providers commitment to service provision</b>		
No	5	1.7
Yes	290	98.3
<b>Enough time take to listen to the complaints of clients</b>		
No	10	3.4
Yes	285	96.6
<b>Ever gone to a health facility and missed ARV</b>		
No	287	97.3
Yes	8	2.7
<b>Service providers flexible to reschedule clinics for clients with genuine reason for changing</b>		
No	225	76.3
Yes	70	23.7
<b>Adherence to principle of first in first out at the care and treatment visits</b>		
No	65	22
Yes	230	78
<b>Clients given an opportunity to choose a clinician during visits</b>		
No	288	97.6
Yes	7	2.4

<b>Clients leaving CTC without being attended</b>		
No	286	96.9
Yes	9	3.1
<b>If Yes response in previous question how many times has that happened</b>		
Never	281	95.3
Once	12	4.1
Twice	1	0.3
Thrice	1	0.3

## **6.5 Service recipient related factors**

### **6.5.1 Participants records on clinic attendance for the past three months**

The recipients were asked whether they ever attended any care and treatment clinic in three months ago, but also from their CTC 1 card the months that have passed since they visited the clinic that they were initially registered for services was calculated and recorded.

The findings were that (189) 64.1% of clients had attended a care and treatment clinic apart from their initial CTC, and the averagely 7.8 months at 95% CI: 7.16 8.52 was recorded since the participants lastly visited the initial clinic, though this could have been due outliers as majority of clients 142 (48.1%) had 3-5 months without attending their original CTC, while only 2(0.7) had finished around 28.5 months without attending as summarised in Table 6.5

**Table 6.5: Participants records on clinic attendance for the past three months**

<b>Variables</b>	<b>Frequency</b>	<b>Percentage</b>
<b>Did attend any CTC clinic last month</b>		
No	106	35.9
Yes	189	64.1
<b>Months passed since last initial clinic attendance</b>		
03-05	142	48.1
06-08	58	19.7
09-11	23	7.8
12-14	31	10.5
15-17	24	8.1
18-20	5	1.7
21-23	3	1
24-26	7	2.4
27-29	2	0.7

### 6.5.2 Service recipient related factors on people living with HIV/AIDS lost to follow up on care and treatment

In the univariate analysis of factors at the individual level of 295 participants, about three-quarters received three lessons prior ARV initiation; some participants (34.2%) did not understand the benefits of good ARV adherence and utilization. There are also (12.2%) participants who use herbal medications as alternative medicines in case their ARV were not available in the clinics whereas others (11.2%) decide to stop using ARV due to side effects but there are (5.8%) who stopped taking ARV medicines because they believe that have been healed by faith.

This study has found out that majority of participants labelled as lost to follow-up were also not members of any treatment support group (88.8%), but it was also noted more than half of study participants declared that their treatment supporters were not aware that they have not attended clinics for the past three months.

**Table 6.6: Service recipient related factors on people living with HIV/AIDS lost to follow up on care and treatment**

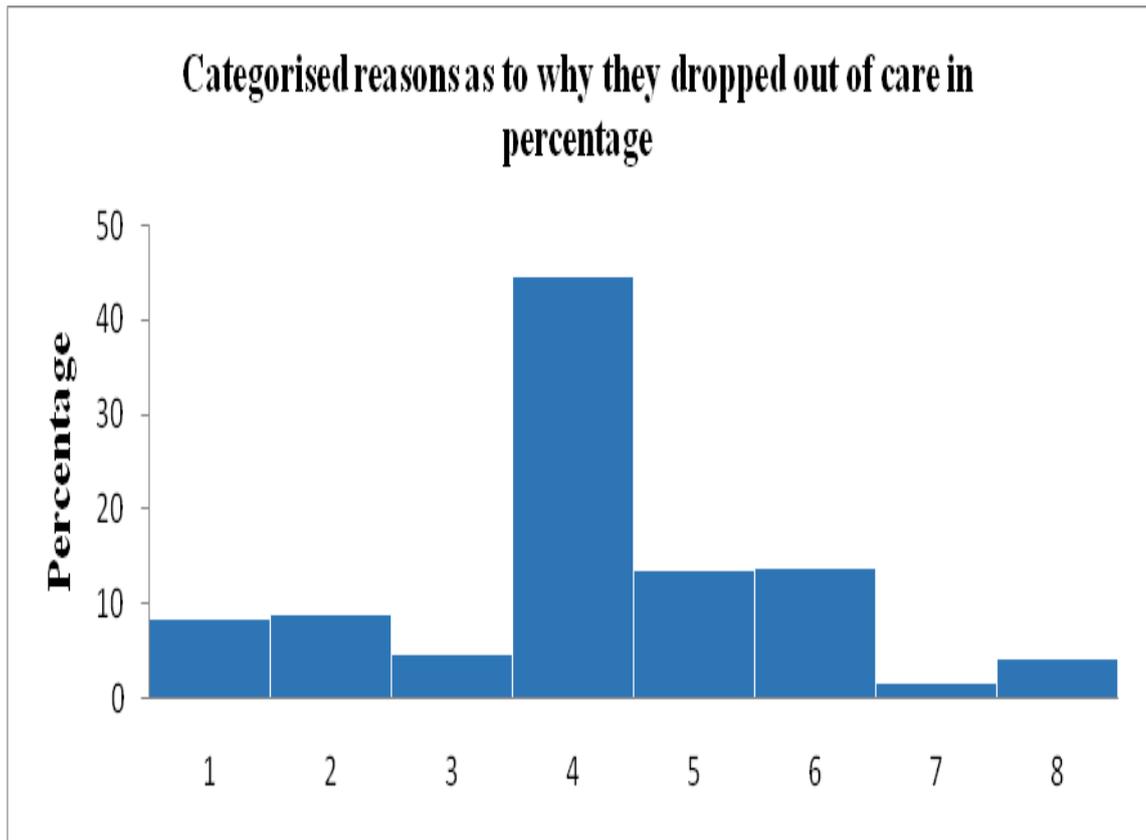
Variables	Frequency	Percentage
<b>Participant awareness on whether facilities checking CD4-count</b>		
No	27	8.5
Yes	270	91.5
<b>Means of transport used getting to a nearby health facility</b>		
Walking on foot	287	97.3
Motor cycle	5	1.7
Car	3	1
<b>Time taken to reach the facility on foot</b>		
0 hour	1	0.3
1 hour	17	5.8
2 hours	99	33.6
3 hours	123	41.7
4 hours	48	16.3
5 hours	6	2
6 hours	1	0.3
<b>Comfortable with the time used while waiting for care and treatment</b>		
No	244	87.2
Yes	51	17.3
<b>If it takes a long time while waiting for care and treatment</b>		
No	244	87.2
Yes	51	17.3
<b>Happy with scheduled days for attending monthly care and treatment clinics</b>		
No	129	43.7
Yes	166	56.3
<b>Comfortable with bureaucracy followed before receiving ARV during clinics</b>		

No	95	32.2
Yes	200	67.8
<b>Lessons attended prior to ART initiation</b>		
1	25	8.5
2	60	20.3
3	210	71.2
<b>Whether understood benefits of good ART adherence and utilization</b>		
No	101	34.2
Yes	194	65.8
<b>Whether income is enough to support for transport fare to the health facility each month</b>		
No	256	86.8
Yes	39	13.2
<b>Use of herbal medications as the alternative</b>		
No	259	87.8
Yes	36	12.2
<b>Stopped using ARV due to side effects</b>		
No	262	88.8
Yes	33	11.2
<b>Have stopped taking medications because were healed by faith</b>		
No	270	91.5
Yes	25	8.5
<b>Whether treatment supporter knows that clients have not attended care and treatment clinics for past three months</b>		
No	178	60.3
Yes	117	39.7
<b>Being a member of treatment support group</b>		
No	262	88.8
Yes	33	11.2
<b>What an individual observes from others that make them not attend the CTC as they previously did</b>		
Distance to facility	49	16.6
Healed by faith	26	8.8
Drug side effects	17	5.8
Travel costs	34	11.5
Stigma	81	27.5
I don't know	31	10.5
Distance to facility and healed by faith	4	1.4
Distance to facility and drug side effects	1	0.3
Distance to facility and travel costs	27	9.2
Distance to facility and stigma	7	2.4
Healed by faith and drug side effects	2	0.7
Healed by faith and travel costs	4	1.4
Healed by faith and stigma	6	2
Drug side effects and travel costs	4	1.4
Travel costs and stigma	2	0.7
Healed by faith and costs	2	0.6

Also during the study apart from the structured questions, participants were given an opportunity to mention what reason that has caused them not to continue attending regularly to the care and treatment sites where they formerly used to attend. Among them, 132 (44.7%) mention travel cost as the major reason but some even mention a combination of travel costs and distance to health facilities through about 40 (13.6%)

had no any reason as to why they have not been able to attend regularly. Further, about the given responses are summarised in Fig 6.1.

**Figure 6.1: Reasons given by clients as to why they did not attend care and treatment clinic as they previously used to do**



Key:

1= Have shifted from original previous CTC using near facility 8.5%, 2= Healed by faith 8.8%, 3= Drug side effects 4.7%, 4= Travel cost 44.7% 5= Have no reason 13.6% 6= Have not started ARV 13.9%, 7= Have shifted from original previous CTC and currently using near facility and due to high travel costs 1.7%, 8= Have shifted from original previous CTC and now using near facility and have not started ARV 4.1%.

## 6.6 Bivariate analysis of variables

The dichotomous variables were cross tabulated against monthly attendance on care and treatment clinic a month before the study was conducted. A Chi-square test was performed to establish the relationship between different independent variables and

participant's attendance to any CTC in three months prior to study as a dependent variable. Those variables, which were statistically significant, had p-value less than 0.005. The  $X^2$  test results, p-value for cross tabulations were determined and summarized in Table 6.7. Majority of the variables that were statistically significant were service recipient related factors.

**Table 6.7: Cross-tabulation of independent variables and the attendance at any care and treatment centre in a month before the study and the P-value significant  $\leq 0.05$**

Independent variables with subcategories		Dependent variable		P-Value
		If attended any CTC in past month		
		NO	YES	
Sex	Female	52	88	0.645
	Male	54	91	
WHO HIV clinical stages	Stage 1 and 2	85	144	0.429
	Stage 3 & 4	21	45	
CD4 Count categorized	$\leq 350$	96	174	0.658
	$>350$	10	15	
Health care staff friendliness	No	10	23	0.475
	Yes	96	166	
Staff communication	No	13	36	0.133
	Yes	93	153	
Staff availability	No	1	5	0.320
	Yes	105	184	
Staff uses harsh language	No	103	184	1.000
	Yes	3	5	
Happy with health staff response	No	1	6	0.428
	Yes	105	183	
Approachable provider	No	2	15	0.037
	Yes	104	174	
Confidential information	No	76	177	0.000
	Yes	30	12	
Reliable HIV information	No	0	3	0.555
	Yes	106	186	
Provider commitment	No	0	5	0.164
	Yes	106	184	
Provider takes time to listen to complaints	No	1	9	0.101
	Yes	105	180	
Ever left CTC unattended	No	103	183	1.000
	Yes	3	6	
Health facility check CD4	No	24	1	0.000
	Yes	82	188	
Ever missed ARV	No	105	182	0.266
	Yes	1	7	
Comfortable with time used waiting for care	No	99	145	0.000
	Yes	7	44	
Takes long time waiting for care	No	99	145	0.000
	Yes	7	44	

Happy with scheduled clinic days	No	48	81	0.715
	Yes	58	108	
Provider flexibility to reschedule	No	79	146	0.598
	Yes	27	43	
Comfortable with clinic bureaucracy	No	44	51	0.010
	Yes	62	138	
Adherence on FIFO	No	63	2	0.000
	Yes	43	187	
Opportunity to choose clinician	No	104	184	1.000
	Yes	2	5	
Understand benefits of ARV adherence	No	72	29	0.000
	Yes	34	160	
Income enough for transport	No	106	150	0.000
	Yes	0	39	
used herbal as an alternative to ARV	No	72	187	0.000
	Yes	34	2	
Stopped ARV due to side effects	No	98	162	0.086
	Yes	8	27	
Stopped ARV due to faith	No	83	187	0.000
	Yes	23	2	
Supporter knows of not attending to clinic	No	92	86	0.000
	Yes	14	103	
Being a member of treatment support group	No	83	179	0.000
	Yes	23	10	

## 6.7 Univariate logistic regression

Following the chi-square test result that showed many variables to be statistically significant with a p-value less than 0.05, then univariate binary logistic regression model was done. The variable that had a confidence interval that includes 1 within its lower and upper limit was excluded. The factors with a p-value less than 0.05 that were statistically significant are summarised in the following Table 6.8.

**Table 6.8: Univariate logistic regression of variables**

Independent variable	Odds ratio	P-value	95% confidence interval	
Approachable health provider	0.223	0.049	.050011	.9950466
Confidentiality	0.172	0.000	.0834834	.3533464
Health facility checking of CD4 count	55.024	0.000	7.32029	413.6016
Takes long time waiting for care	4.292	0.001	1.857405	9.91601
Comfortable with time waiting for care	4.292	0.001	1.857405	9.91601
Comfortable with bureaucracy during services	1.92	0.011	1.16191	3.173712
Adherence to first in first out during services	136.988	0.000	32.25473	581.7988
Adherence benefits	11.684	0.000	6.619495	20.62179
Use herbs as alternative to ARV	0.023	0.000	.0053033	.0967239
Stopped ARV due to faith	0.039	0.000	.0088933	.1675006
Treatment support aware of client not attending clinic	7.87	0.000	4.187711	14.79178
Being a member of treatment support group	0.202	0.000	0.0917983	0.4427516

#### **4.8 Multivariate analysis of factors associated with lost to follow-up**

A backward multivariate analysis approach was done using Binary Logistic Regression Model at 95% confidence interval to estimate the relationship of the independent variable that was found to be significant in univariate logistic regression with participant attendance to care and treatment. These were approachable health care staff, confidentiality, checking of CD4 count, comfortable with time used while waiting for care, whether it takes long time to wait for services, happy with bureaucracy during service, if providers adhere to first in first out principle, enough income to support transport fare, participant understanding of adherence benefits, use of herbal medications as alternative to ARV, stopped using ARV due to faith, treatment supporter awareness of participant not attending clinics and if participant is a member of treatment support group. Table 6.9 gives a summary of all variables that were found to be statistically significant with a p-value less than 0.005 but also their odds ratio and the confidence intervals at 95%. Thus we have evidence which suggests that there is a relationship in the population between independent variables with p-values < 0.005 and attendance to care and treatment clinics if variables are controlled.

With the findings in the multivariate analysis table, there were unusual findings, for those who agreed that providers adhere to first in first out principle provider adherence to first the odds ratio was about 800 as compared to those who disagreed. Furthermore participant awareness on whether their facilities check CD4 count with the significance of p-value 0.000 was 265 times for clients that know the availability of CD4 check-up at the clinic. After adjusting for other variables the variables summarised in Table 6.9.

**Table 6.9: Multivariate logistic regression model to determine factors associated with LTFU, against the dependent variable attending care and treatment in the last three months**

<b>Independent variables</b>	<b>Odds ratio</b>	<b>P-value</b>	<b>(95% Confidence interval)</b>	<b>Confidence</b>
Approachable health care staff	0.0001714	0.000	2.79E-06	0.01051
If participant is aware that their facility checks CD4 count	265.3073	0.001	11.02467	6384.587
Comfortable with waiting time during service	16.86782	0.02	1.555913	182.866
Provider adherence to first in first out	802.2018	0.000	50.70592	12691.37
Participant understands benefits of ARV adherence	20.77668	0.000	5.665568	76.19193
Participants use of herbs as alternative to ARV	0.0137158	0.000	0.001905	0.098752
Stopped using ARV due to faith	0.0026163	0.001	7.76E-05	0.088254

## CHAPTER SEVEN

### DISCUSSION OF THE FINDINGS

#### 7.1. Socio-demographic and clinical findings

This study is among other studies such as (Ahmed, Gugsu, Lemma, & Demissie, 2013; Alverex-Uria, Naik, Pakam, & Midde, 2013; Asimwe et al., 2015; Roura, Busza, & Urassa, 2009) that have assessed the factors leading to increased lost to follow-up among HIV infected individuals that are initiated on care and treatment services. In this study concerns related to sustained drop out of care among the HIV infected individuals in Kyerwa, despite receiving free antiretroviral therapy is reported. This evaluation also was able to assess the success of the activities that were intended to improve quality of life of individuals infected with HIV through increased access and availability of ARV to eligible people living with HIV/AIDS.

Total patient follow-up of care and treatment is essential both for care of individual client and for monitoring and evaluation of outcomes of ART programmes. In the present study factors that are associated with sustained high adult drop out on HIV care and treatment services were categorised as provider related, service accessibility and availability, system related and also as service recipient related factors. Each category was further fragmented into related specific factors that generated details of reasons that are related with adult lost to follow up.

The mean age of participants was 34 years where majority 53.6% of participants were aged (31-40 year) almost similar to a study done in Ethiopia (Tsega et al., 2015). The findings also showed that the group of youth aged between 21-30years which is about 28.1% of the participants was among the groups with increased rate of lost to follow up. This means that a large group of adults are likely to continue being lost to follow up. But age was among the factors that were not significantly associated with lost to follow-up different to a study done in India (Uria et al., 2013).

The married participants were found to have a significant contribution to the number of clients reported as lost to follow-up on care which contributes to 213 (64.5%) of all study participants. Effort has to be made to overcome the situation and break the

uprising situation as couples have shown a large number of clients lost to follow-up in this study.

Lack of education can be related to poor health seeking behaviour (Musoke, 2014). The majority of the participants that is 223 (75.6%) had only completed primary school level. This level of education sometimes is associated with lack of understanding the theories that an individual has to go through so as to get acquainted with knowledge on HIV/AIDS care and treatment. But also to understand the benefits of good ARV adherence and then have a good follow-up level of knowledge needs to be cracked down and digested to a level that even those who never went to school can grasp. This is a concept behind that the diseases never choose the elites and non-elites everyone is at risk. Thus to achieve proper adherence and hence have a significant reduction of patient drop out of care the HIV/AIDS care and treatment service need to be integrated into care seeking habit (Joglekar et al., 2011; Roura et al., 2009).

There was no much difference in gender despite the random selection of the anonymous identification numbers from the record of lost to follow-up obtained at the health facility. The proportion for female and male participation was 50.8 to 49.2 respectively. This means according to this study that regardless of gender all HIV/AIDS are in one chance or another likely to drop out of care. This has been a bit different from others studies both men and women participated in responding to the questionnaire (Hailasillassie, 2014).

This study found that patients who were lost to follow-up also included those between WHO clinical stage I and II about (77.6%) similar to other studies (Agu et al., 2012; Hassan et al., 2015). The clients with clinical stage one and two have no very life threatening features, thus they are ineligible to start ARV, and thus they are scheduled for a monthly clinic visit for follow up on their progress. It could be that these clients see no reason of sustained attendance to the care and treatment sites each month, since they consider it as gaining nothing and after all it is costly for some that travel quite a long distance to a facility since this could be accompanied with use of money for fare and food during the visit.

Health service providers are trained on appropriate HIV/AIDS-related cases management (MoHSW & NACP, 2012). With the intention of the programme that, they had to retrain clinic staff in updated HIV management protocol so that providers are capable of diagnosing the case and severity of the disease. HIV/AIDS usually worsens as the clinical condition of the patient is between WHO clinical stage three and four (Boniphace et al., 2011). At those stages, the clients are liable to start taking ARV regardless of the CD4-count cells (WHO, 2013a). The study found out that, majority of clients 91.5% had CD4 count  $\leq 350$  which indicates they were eligible to be on ART (Watt et al., 2010). Being lost to follow up on care while the client is eligible to be on lifelong treatment means the patient predisposes him/her(self) to the development of medicines resistant strains but also worsening the clinical condition.

Also, the study found that clients have income that ranges in between (0-5000 Tsh) 93.9%, which is not enough to support them for transport fare to attend regularly at the clinics during monthly visits. These findings could be associated with the results that most of the participants walk on foot to the health facilities of which 41.7% walk for three hours, while 33.6% use two hours, 16.3% use four hours and the rest use one hour. The results illustrate how individual-level, social and economic factors influence high HIV clients get lost to follow up on care and treatment in rural areas of Kyerwa district. In some studies (Mill et al., 2006) socio and economic reasons were regarded to have fewer effects to influence adherence. Compared with other studies (Tsega et al., 2015; Babigumira et al., 2009) this study found out that income status of the patient is related with ART adherence. This finding concurs with other studies (Hailasillassie, 2014; Reda & Biadgilign, 2012;) which regarded low income to be a factor contributing to patients lost to follow-up care and treatment. The programme had among its activities to collaborate with NGOs and other agencies that can provide financial and social support and income generating assistance to people living with HIV. This seems to have a low pace since the income of the clients is still inadequate thus unable to have good follow-up of care. The CTC are still not close to clients that it takes much time about 2.8 hours (95% CI: 2.65-2.86) to walk on foot or travel for monthly clinic visits. Thus either the costs of transport or distance to the medical facilities were influencing patient attrition from ART care because clients have to incur cost to travel to the facilities because they are far and

need a lot of time to walk to facilities in this community. Similar to other previous studies (Mill et al, 2006; Ware et al, 2009) that have not found the correlation between lower income and adherence to treatment other findings have reported the negative impact of livelihood constraints on treatment adherence. Our study findings suggest that in remote areas where poverty has become common where a stable source of income is undetermined, individuals are liable to keep away from actions that would render them to further socio-economic powerlessness though statistical significance to support this.

## **7.2 Service provider related factors**

Of the 295 clients approached 88.8% declared that the health providers at the clinics they used to visit were friendly though 16.6% did not enjoy the way providers communicate with them. Hitherto results were albeit contradicting since only 2.7% of the participants said that health providers use harsh language and 97.6% were happy with the way health staff responded to their requests.

Furthermore among the factors that the study attempted to relate with patients lost to follow-up only staff approachability was significantly associated, with P-value < 0.05. It could be that the data were not enough to accept the hypothesis that approachable health staff influence patient retention on care.

## **7.3 Health system related factors**

Frequent missing of the providers at the care and treatment sites was thought to be related to poor client attendance. Since the process of attending clinics takes valuable time but also the meagre resources, thus visiting a clinic while the possibility of receiving care is a probability would have discouraged patients to attend. Contrary to that perception this study found out that 289 (98%) never missed health staff at care and treatment sites during the scheduled visits.

The HIV/AIDS care section under the district medical officer in collaboration with the non-governmental organisation had among their plans to make sure that ARV medicines are readily available at the CTC sites. Also, they set up a plan to make sure that no unnoticed stock out of medicines to the whole district through their integrated logistic system.

The implementation and success of this were measured through asking whether they ever visited a clinic and missed their ARVs. The finding was that 287 (97.3%) of participants had not missed ARVs at any time they attended CTC.

Having good provider-client relationship was thought and has been vital to improving adherence to care and treatment (Goold & Lipkin, 1999). HIV/AIDS like any other diseases the client has the right to choose a provider that he/she is comfortable with so as to express the well-being. A good relationship between provider and client open a room for the providers to know where to intervene in case the patient does not do well with particular treatment (Bofill et al., 2014). This study found that 97.6% of participants had no opportunity to choose a clinician to attend them during their visits to the clinic even though 98.3% recognised the health provider's commitment to work.

#### **7.4 Service recipient related factors**

This objective was meant to find out what could be the reasons from client side that are related to drop out of care and hence failure to regularly attend the clinics. The study began by assessing the level of awareness of services that are provided at the health facility they used to attend for care and treatment such as being aware of CD4 count testing. It was planned that the project had to improve the capacity of the laboratories to carry out a CD4 investigation. All facilities that study participants were coming from are doing CD4 testing since it was possible to read the last CD4 count as one of the study variables needed. Though few clients 25 (8.5%) did not know whether the facilities they attend does CD4 count investigation.

Also, awareness of availability of checking CD4 count at the facilities was significantly associated with lost to follow-up after adjusting for other factors in the model (OR=. 265.3073, 95% CI: 11.2-6384.5) with  $p < 0.05$ . The availability of such service motivates and encourages service recipients to keep attending the clinics as they sure of checking their progress (Mukherjee, 2006; Mutasa-Apollo et al., 2014) the findings of this study have been contrary to what is expected.

Easy access to service promotes adherence and follow up of the service (Tweya et al., 2014). It was noted that 287 (97.3) walk on foot to attend the care and treatment

clinics. Despite being within the walking distance, majority of patients 123 (41.7%) use three hours, and 99 (33.6%) use two hours yet there other 48(16.3%) who approximately use four hours of walking till they reach the clinic. Multiplying twice the time of travel in each case it means much time is used for a to and fro movement while seeking for HIV/AIDS care and treatment.

Most of the participants reported that it takes a long time while waiting for care 244 (87.2%) but yet participants were comfortable with time spent while waiting for care treatment services at the clinic with (OR= 16.87, 95% CI: 1.56-182.87) with significant association to lost follow-up  $p = 0.02$ . Never the fewer respondents were comfortable with it contrary to other studies (Muchedzi et al., 2010) where clients were dissatisfied with long waiting time.

Due to a shortage of human resource, the care and treatment sites provide other health-related intervention to non-HIV infected individuals. With that, there are fixed schedules with a reasonable number of clients to attend clinics on particular days. But in mind also these appointed days match with the number of medicines to be supplied to the recipient so as to avoid missing medicines before the next visit. With that patients are supposed to attend CTC on regular basis as allocated by the clinician who attends that patient. Participants were asked whether they are usually happy with days/dates that are scheduled for monthly visits. It was found that 43.7% almost coming to half of the participants were not happy with it.

It is normal practice before the provision of health care service patients have to be registered and organised to receive service accordingly. This similar practice also applies to HIV/AIDS clients, that when they attend clinics they have to be registered, get daily planned lessons pertaining to HIV/AIDS and all other preliminary stages. The study thought this bureaucracy could be annoying to clients hence decide to quit care. But the finding of the study is that 67.7% of participants were comfortable with the bureaucracy. The remaining percent is significant to follow so that they are not dropping out of care due to unpleasing procedures to go thru during service attendance.

Prior to ARV initiation, the eligible clients are supposed to have at least three sessions of adherence counselling. After these sessions, the patient is assessed to know whether a client has understood the adherence classes explained and is ready to start ARV. Incompletion of pre-ART adherence as noted by this study that 25 (8.5%) and 60 (20.3%) were initiated ARVs with after only attending one to two adherence sessions respectively. Out of 295 participants, 101 (34.2) declared to have an inadequate understanding of benefits of good ARV adherence.

The availability and use of alternative medicine to manage HIV/AIDS were presumed by this study. Some of the participants 33 (11.2%) declared the use of herbs as an alternative to ARV. This study was able to establish a significant relationship between uses of herbs and failure to attend care and treatment among HIV/AIDS patient with (OR= 0.01, 95% CI 0.001905-0.098752). The herbs that are used have no scientific proof of whether they can be used to fight the virus. It is often difficult to predict how medicines (ARV) or herbs that target one part of the immune system will impact on another part. Patients who decide to use herbal medications as an alternative to antiretroviral therapy are at higher risk of poor adherence and hence resort to drug resistance (Peltzer et al., 2010). This has significant effects towards struggles of retaining patients on care and treatment. While the programme is struggling to maximize the retention clients on care and treatment service, there some that have taken the other route towards managing their HIV/AIDS status. Before coming up of the ARV and prior to the client being diagnosed as HIV/AIDS positive clients may have been using local herbs to treat another disease. In that case, it may be that again even when an individual has been diagnosed HIV-infected the same solution could be resorted to for treatment. With this, there is a need to have means to follow the clients at the family level and have clues on how helpful herbs are and establish the means and be able to counsel on proper drug adherence and take the right means of handling the disease.

The undesired side effects due to medicines that were taken may have potential result towards sustained adherence to clinics. The severity of side effects at the individual level may demoralise the service user and hence drops out of care. Of those that mentioned drug side effects as their reason to why they have dropped out of care

said the reactions after taking medicines were too severe hence they could not continue using medicines that were compromising their health which is a finding similar to other studies that reported in other studies about drug side effects contribution to patients drop out of care (Kim et al., 2016; Koethe et al., 2009). But this study found out that only 33 (11.2%) of approached participants stopped using medicines and hence attending clinics due to side effects of ARVs. Data have not been adequate to establish the relationship between ARV side effects and lost to follow-up.

Availability of various religious beliefs was also thought to interfere with patient adherence to care and treatment. Some of the participants have stopped attending care and treatment clinics but also believe that they have been healed thru their faith and hence do not take ARV. This study found out a relationship between not attending care and treatment clinic and the patient decision to stop using ARV due to faith being significant (OR= 0.00, 95% CI 7.76 – 0.088). Which means the odds ratio of that has stopped attending clinic due to their faith is 0.0026 times for those who are lost to follow-up adjusting for other factors. The finding is backed up by findings from other studies (Chesney, 2000; Monjok et al., 2010). Religious belief especially those preaching of the healing power and their demonstrations scattered all over the country that some religious prophets have the ability to heal and cure all disease including HIV/AIDS. Some of HIV-infected individuals may stop using ARV and thus quit clinic attendance. The study also found that some clients stopped medications because of the claim that were healed by faith, which is a finding similar to other studies (Musheke et al). This was found to add on reasons for poor retention in care. Other studies (Tweya et al., 2014) have found that people stop following up medications due to the belief that they have been healed thru prayers and use of holy water that is believed to heal all sorts of illness and HIV infection included. This study has been able to prove the hypothesis that religious beliefs are related with lost to follow-up on care and treatment.

It has been found by this study that there were PLWH who stopped following up care and treatment regularly due to fear of being stigmatised. This has been similar finding with other studies that have shown stigma to be a common reason for client's

poor adherence (Monjok et al., 2010). Stigmatization of persons living with HIV/AIDS discourages people to continuously seek for care in case they experience that at health facilities and even in their community (Li et al., 2007).

Due to fear of being labelled by the community but also the family stigma has been reported to negatively affect adherence on HIV care and treatment in sub-Saharan Africa. This has gone far that patients even fail to disclose their HIV status (Hassan et al., 2015; Rosen et al., 2007b). In this study, stigma has been found to have a 27.9% contribution towards an increase in lost to follow in this study area slightly different from other studies (Tsega et al., 2015).

When individual participants were asked to mention what they observe from others as a reason to drop out care in their own words stigma was named as among the common observation. Others went further to say that stigma leads to silent self-transfer by clients to other health facilities without following up proper referral procedure hence it leads to being categorised as to lost to follow-up similar to other studies (Berheto et al., 2014; Mills et al., 2006). This makes a total percentage of clients who are regarded as lost to follow to increase. This finding is also similar to other studied that came up with the self transfer as a factor towards a continued increase in a number of HIV/AIDS clients regarded as lost to follow-up (Assefa et al., 2010; Brinkhof et al., 2009; Estill et al., 2014).

Treatment support groups have an important role towards enhancing proper ART adherence. These groups bring closer all HIV-infected individuals and hence they could be used to identify patients with good or poor progress, but also those who are incapacitated so that proper action can be done to improve the health of such individuals (Reblin & Uchino, 2008; Simoni et al., 2008). The treatment support groups have a role in reminding, encouraging and emphasizing the importance of good adherence to medicines (Berheto et al., 2014; Johnson, 2014). In this study, it was found that awareness of treatment supporter about clients not regularly attending the clinic was related high lost to follow-up. This is because the majority of clients 178 (60.3%) confirmed that all the participants that were approached their treatment supporters were not aware that their fellow has not attended care and treatment centres for past three months.

The worse scenario observed in this study was that 263 (89.2%) of study members were not of any treatment support group. The programme also intended to support the development of treatment support groups but the evaluation has found out that more than three quarters were not members of any treatment support group. On average the value of variable attendance to CTC in past three months is lower for members who are not in support groups by about 0.18 though there is strong evidence of a relationship with p-value 0.001 in univariate logistic regression. After controlling other factors, being a member treatment support group was weak and negatively associated with lost to follow-up as  $OR < 1$ .

The programme also planned to develop a short course for HIV case managements, drug adherence, infection control and counselling for health care workers. In this study, it was found that PLHIV had a good relationship with health service providers which is different from the previous studies (Ware et al., 2013a) which state that harsh treatment and bad language have influence toward regular attendance for care and treatment. This study found out results that were different to the findings in North America study (Mill et al., 2006) where it was stated that the major barrier to ART adherence was due to poor patient-clinician relationship. Patients were comfortable with responses from their health care providers contrary to the findings from others studies (Ware et al., 2013) where some clients expressed that feeling of shame at missing visits and fear of clinic staff's negative response to their absences in previous clinics. Thus it is possible that, implementation of that activity could have contributed to lead to improved staff behaviour and hence the change in their attitudes.

Also, factors like long waiting times for medical care, and being comfortable with time spent during care were positively responded to. A significant proportion of participants responded to be comfortable with the time they spend to the health facility while waiting for care and treatment so long as the principle of first in first out is adhered. These were not found to be associated with a sustained increase in lost to follow-up.

Since the beginning of ART care, the health sector has tried many support strategies to improve adherence (Ware et al., 2013b). Similar to findings from previous studies (Joglekar et al., 2011) long waiting times at health facilities affected patient access to treatment. Although 76.3% of study participants reported that service providers were not flexible to change the scheduled monthly clinic days regardless of the genuine reason a client gives, the majority of the participants were happy with the days allocated to them for the next monthly visits.

The health system has factors that the study viewed so as to overcome the challenges of lost to follow-up included improving the quality of service providers, accessibility, and availability of services. Service provider related factors include their hospitality to the clients so that they can be attracted to keep following up the treatment. Staff friendliness, communication with clients, staff responses to client needs, and their competence to service provision are among the key features that were studied in this programme evaluation. Dissatisfaction with healthcare services were major reasons for patients being non-adherent and lost to follow-up (Bezabhe et al., 2014). Approachable health provider was statistically significant with a p-value of 0.000 as shown in table 4.6. Even though it is highly significant, it influences lost to follow-up negatively as evidenced by negative sign of the coefficient in multiple linear regression models. Some studies have shown that motivation of clients especially those ineligible to start ART to keep follow of care and treatment clinics but also consider giving medicines for a long time to minimise transport costs to the clients (Mugglin et al., 2012; Mugglin et al., 2014).

The study has come out with the possibility that probably the increasing number of lost to follow-up could be associated with the uncoordinated information tracking system. There are clients who self-transfer to other facilities even within the same district. Self-transfer of patient as in other studies (Johnson, 2014) was also found to contribute to lost to follow up as found in this study. There are significant numbers of participants who were approached as lost to follow-up but then they had self-transferred to other clinics without notification to initial care and treatment clinics as found in other studies (Makunde et al., 2012).

Almost 8.5% of the clients that were approached reported to collect ARV at a new site which is closer and was misclassified as LTFU at their initial ARV clinics. With such findings of self-transfers there could be a number of other clients who could still be considered lost to follow-up while they transferred to other facilities (Glidden et al., 2010; Yiannoutsos et al., 2008). If there was an improved information system but also sticking to the protocol of patient transfer also clients that are recorded as lost to follow-up could be less than which is currently recorded.

### **7.5 Programmatic implications use of findings for strategic planning**

The study found that there were clients who live far away from the health facilities such that they use a long time to travel for ARV collection thus there are still few accessible care and treatment centres. The project has to strengthen its efforts toward improving income-generating activities since the clients that were involved in the study have low income. Self-transfer from one facility to another without notice to former care and treatment centre may have alerted that some of the patients recorded as lost to follow-up are still on care though at different sites since they did not follow the transfer protocol. It was seen that there were few treatment support groups in the area. With such findings there is need to improve the accessibility of HIV care and treatment centres, also need to establish income generating activities for the clients. There is a need to establish and encourage treatment support groups as these may aid in overcoming stigmatization but also promote drug adherence. It is important if recounting and cross checking of clients who are alive and still on ART is done so as to obtain the actual number of clients on care and treatment.

### **7.6 Conclusions and recommendations**

Without harmonizing access to ART, there is a risk of emerging drug-resistant HIV viral strains that would result in treatment failure and hence high mortality rate. This is a potential threat and could hold back efforts to overcome HIV/AIDS hence interfere with future treatment options and lead to the transmission of drug-resistant strains of HIV. Clients being lost to follow-up from ART care are not entirely an individual choice but affected by a complex and dynamic interaction of personal, social, health system and structural-level factors.

Even for the most motivated patient, being on life-long treatment is not an easy task. Patients have to weigh the needs of treatment with the effects of accessing treatment on their social, physical, mental and economic well-being.

After adjusting for other studied factors that were studied and included in the model it was found that factors such as provider approachability, participant's awareness on checking CD4, use of herbal medicine and stopping medication due to faith were more likely to contribute to lost to follow up. Most of the finding that has been identified was much more related to lack of adequate knowledge on benefits of good adherence, thus the programme implementers need to strengthen on adherence counselling training for both providers and recipients. Moreover, results of this study have opened room for further researchers to determine the magnitude of the effects caused by the identified factors.

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## APPENDICES

### APPENDIX I

#### 6.1 Questionnaire- English Version

##### CONSENT

I am Florian Mutasingwa, a masters student from Mzumbe University doing a research on factors associated with high attrition rate on HIV care and treatment services in Kyerwa district. This questionnaire intends to obtain information from you about the factors leading to increased attrition on HIV care and treatment services from our facilities in Kyerwa district. The information you will reveal to me shall remain confidential but will be used to complete my research and also they will help the district to set up intervention to rescue the situation.

You have all rights to participate in this research and responding to this questionnaire, but even if you accept to participate you still have the opportunity to withdraw from the activity

To participate in this study I please ask you to sign this consent. Signature-----

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6.3 Questionnaire No..... Name of the Hamlet.....

Name of facility the client usually attends for care and treatment clinics.....

Number	Question	Response	Code
A	Background information		
	1.Age	..... Years	
	2.Sex	Female Male	1 2
	3.Marital status	Single Married Widow Divorced Living together	1 2 3 4 5
	4.Education level	Not completed STD seven Completed STD Seven Completed Form IV Completed Form VI Certificate/Diploma level	1 2 3 4 5 6

		Graduate	
	5. Employed	No Yes	0 1
	Did you attend any CTC centre in the last month?	No Yes	0 1
	6. How many months passed since last clinic attendance	-----	
	7. From CTC-1 card read last CD4 count	-----	
	8. From the CTC-1 card read HIV clinical stage	Stage 1 Stage 2 Stage 3 Stage 4	1 2 3 4
<b>B.</b>	Objective 1: Service provider related factors		
	9. Are the health staff friendly at the facility you used to collect your medicines?	No Yes	0 1
	10. Do you enjoy the way health staff communicate with you?	No Yes	0 1
	11. Are health care staff providing care and treatment readily available when you visit the clinics?	No Yes	0 1
	12. Do health staff use harsh language when attending you?	No Yes	0 1
	13. Are you happy with the way the health staffs respond to your requests?	No Yes	0 1
	14. Is it easy for you to approach the health care provider?	No Yes	0 1
	15. Have you ever heard in streets the confidential information that you previously revealed to the CTC health provider?	No Yes	0 1
	16. On your own opinion were the health information given to you about HIV /AIDS care and treatment reliable?	No Yes	0 1
	17. On your own views do you think that the health service providers are committed to providing services	No Yes	0 1
	18. Do health care providers take enough time to listen to the complaints that you explain to him/her?	No Yes	0 1
	19. Have you ever gone ever gone for care and treatment centre and but the health providers were not available and you left without being attended?	No Yes	0 1
	20. If Yes response for question 19 how many times has that happened to you?	.....	
<b>C</b>	Objective 2 Service accessibility and availability related factors		
	21 Do they check for CD4 count at the facility that you usually go to for care and treatment service?	No Yes	0 1
	22. Have you ever gone to a health facility and missed your ARV?	No Yes	0 1
	23. Which means of transport do you use getting to a nearby health facility?	Walking on Feet Motor Cycle Car	1 2 3
	24. How long does it take you to reach the health facility if you walk on foot?	..... hours	
<b>D</b>	Objective 3: Service provision system related factors		
	25. Are you comfortable with the time you use while waiting for care and treatment services at the health facility	No Yes	0 1
	26. Does it take a long time while waiting for care and treatment services?	No Yes	0 1

	27. Are you usually happy with the scheduled days for you to attend the next monthly care and treatment clinics?	No Yes	0 1
	28. Are the service providers flexible to change for you the scheduled days in case you have a genuine reason for changing?	No Yes	0 1
	29. Are you not comfortable with the bureaucracy followed before you receive your ARV during the clinics	No Yes	0 1
	30. During the care and treatment clinics is the principle of first in first out adhered at the care and treatment clinics?	No Yes	0 1
	31. Are you given opportunity to choose the clinician that you are comfortable to attend you during the care and treatment visits?	No Yes	0 1
	32. How many lessons did you attend prior to ARV initiation?	One Two Three	1 2 3
	33. Did you understand the benefits of good ARV adherence and utilization?	No Yes	0 1
	34. What is your average monthly income in TSH?	.....	
	35. Is it enough to support you for transport fare to the health facility to collect your ARV each month?	No Yes	0 1
	36. In case you don't go to collect your ARV and it happens they are finished do you use herbal medications as alternative?	No Yes	0 1
	37. Were the ARV causing severe side effects to you that you decided to stop going to collect them each month?	No Yes	0 1
	38. Have you stopped taking the medications because you were healed by your faith?	No Yes	0 1
	39. Does your treatment supporter know that you have not attended the care and treatment clinic for the past three month?	No Yes	0 1
	40. Are you a member of treatment support group?	No Yes	0 1
	41. What reasons make you as an individual not to attend CTC clinic as you previously did?		
	42. In your experience, what you observe for others not attending the CTC as they previously did?		

## APPENDIX II

### 6.4. Dodoso la kiswahili

Ridhaa ya kushiriki utafiti

Mimi Florian Mutasingwa mwanafunzi wa shahada ya zamili chuo Kikuu cha Mzumbe ninafanya utafiti kuhusiana na sababu zinazohusiana na kutafuta sababu ya kuongezeka watu kuacha kutumia dawa za kufubaza virusi vya UKIMWI katika wilaya ya Kyerwa. Taarifa utakazo nieleza zitabakia kuwa ni siri ila zitanisadia mimi kuhitimisha utafiti ambayo ni sehemu ya masomo yangu. Lakini pia taarifa hizi zitatoa mwanga na hivyo kuisaidia wilaya kuweka mikakati kuhakikisha tatizo la wagonjwa kuacha dawa linapungua na kuweka mikakati ya jinsi gani watu walio acha dawa wanaweza kusaidiwa.

Unayo haki kuamua kushiriki au kutoshiriki katika utafiti huu na kujibu maswali katika dodoso hili; Lakini pia pamoja na kukubali kushiriki unayonafasi ya kujiondoa na kuachana na zoezi hili endapo utajisikia na kutoendelea.

Ili kuendelea na utafiti huu nakuomba utie saini yako kukubali na kuridhia

Saini/Dole gumba-----

6.5 Dodoso No..... Jina la kitongoji.....

Namba	Maswali	Majawabu	Msimbo
A	Taarifa za mshiriki		
	1. Umri	..... Miaka	
	2. Jinsia	Kike Kiume	1 2
	3. Hali ya Ndoa	Sijaolewa/sijaoa Nimeolewa/nimeoa Mjane/Mgane Talaka Naishi pamoja bila ndoa	1 2 3 4 5
	4. Kiwango cha elimu	Hakuhitimu darasa la 7 Darasa la saba Mhitimu Kidato cha IV Mhitimu Kidato cha VI Ngazi ya Cheti /Diploma Mhitimu chuo Kikuu	1 2 3 4 5 6
	5. Umeajiriwa	Hapana Ndiyo	0 1
	Je mwezi uliopita umewahi kuhudhuria CTC mahali popote?	Hapana Ndiyo	0 1
	6. Imekwisha pita miezi mingapi tangu hudhuria lako la mwisho kwenye kliniki yako uliyokuwa ukiitumia mara kwa mara?	-----	
	7. Kutoka kadi ya CTC-1 soma CD4 za mwisho	-----	
	8. Soma daraja la Maambukizi ya HIV kutoka kadi ya CTC-1	Ngazi 1 Ngazi 2 Ngazi 3 Ngazi 4	1 2 3 4
B.	Lengo 1: Sababu zinazohusiana na watoa huduma		
	9. Je watoa huduma za afya katika kituo unakochukua matibabu wako kirafiki?	Hapana Ndiyo	0 1
	10. Je unafurahishwa na jinsi watoa huduma za afya wanavyo ongea na wewe?	Hapana Ndiyo	0 1
	11. Je watoa huduma za afya hususani kwenye kliniki zako huwa wanapatikana kirahisi?	Hapana Ndiyo	0 1
	12. Je watoa huduma za afya hutumia lugha ya ukali wakati wanapo kuhudumia?	Hapana Ndiyo	0 1
	13. Je unafurahishwa na jinsi watoa huduma za afya wanavyoshughulikia mahitaji yako?	Hapana Ndiyo	0 1
	14. Je ni rahisi kwako kumfikia/ kukutana na mhadumu wa afya?	Hapana Ndiyo	0 1
	15. Umewahi kusikia taarifa zako za magonjwa ulizomweleza huduma za CTC kwa siri zikizagaa mtaani?	Hapana Ndiyo	0 1
	16. Kwa maoni yako unadhani taarifa kuhusu virusi vya UKIMWI/ UKIMWI ni za kuaminika?	Hapana Ndiyo	0 1
	17. Kwa maoni yako binafsi je unadhani wahudumu wa afya wanayo nia katika kutoa huduma ya afya?	Hapana Ndiyo	0 1
	18. Je wahudumu wa afya wanatoa muda wa kutosha kusikiliza malalamiko/matatizo mgonjwa anayomweleza?	Hapana Ndiyo	0 1
	19. Je ulishawahi kwenda kufata huduma kituo cha afya na usiwakute wahudumu kituoni na ukaondoka bila kuhudumiwa?	Hapana Ndiyo	0 1
	20. Kama jibu ni ndiyo kwa swali la 19 je ni mara ngapi jambo limewahi kukutokea?	.....	

C	Lengo la 2 Sababu zinazohusiana na ufikikaji na upatikanaji wa huduma		
	21. Je katika kituo cha afya unakopata huduma za afya je wanapima CD4?	Hapana Ndiyo	0 1
	22. Je umewahi kwenda kituoni na kukosa ARV?	Hapana Ndiyo	0 1
	23. Je unatumia usafiri gani kuendea kituo cha huduma za afya kilichopo karibu?	Kutembea kwa Miguu Pikipiki Gari	1 2 3
	24. Inakuchukua saa ngapi kufikia kituo cha afya ukitembea kwa miguu?	..... saa	
D	Lengo 3: Sababu zinazohusiana na mfumo wa utoaji huduma		
	25. Je unafarajika na muda unaoutumia wakati ukisubiria huduma za matibabu katika kituo cha kutolea huduma za afya?	Hapana Ndiyo	0 1
	26. Je inakuchukua muda mrefu sana kusubiri huduma za matibu ya UKIMWI?	Hapana Ndiyo	0 1
	27. Je kila mara unafurahishwa na tarehe unazopangiwa kufuatilia matibabu kwa kliniki ya mwezi unaofuata?	Hapana Ndiyo	0 1
	28. Je unapokuwa na sababu za msingi watoa huduma huwa wapo tayari kukubadilishia siku ya kurudi kliniki?	Hapana Ndiyo	0 1
	29. Je unafurahishwa na taratibu unazopaswa kufata kabla ya kupewa dawa za ARV kila mara uendapo kliniki?	Hapana Ndiyo	0 1
	30. Je wakati wa kliniki kanuni ya wa kwanza kufika ndie wa kwanza kuhudumiwa na wa mwisho kufika ndiye wa mwisho kuhudumiwa inazingatiwa?	Hapana Ndiyo	0 1
	31. Je huwa unapewa nafasi ya kuchagua mhudumu gani unayependa akuhudumie ?	Hapana Ndiyo	0 1
E	Lengo la 4. Sababu zinazohusiana na mpokea huduma (mteja)		
	32. Je ulihudhuria mafundisho mara ngapi kabla ya kuanzishiwa dawa za ARV?	Mara moja Mara mbili Mara tatu	1 2 3
	33. Je ulifahamu faida za kuzingatia matumizi bora ya ARV?	Hapana Ndiyo	0 1
	34. Kipato chako kwa mwezi ni kiasi gani kwa fedha za kitanzania?	.....TSH	
	35. Je fedha hizo zinasosha kukupatia nauli ya kufata matibabu ya ARV kila mwezi?	Hapana Ndiyo	0 1
	36. Ikitokea hujakwenda kuchukua dawa zako na ikatokea zimekwisha je huwa unatumia dawa za mitishamba kama mbadala wa ARV?	Hapana Ndiyo	0 1
	37. Je madhara yatokanayo na utumiaji wa ARV ndiyo yalipelekea wewe kuacha kufuatilia huduma za matibabu kila mwezi?	Hapana Ndiyo	0 1
	38. Je uliacha kufuata dawa na matibabu ya UKIMWI kwa sababu imani yako ya Kidini imekuponesha?	Hapana Ndiyo	0 1
	39. Je msaidizi wako kwenye ufuasi wa dawa anafahamu kuwa hujahudhuria matibabu kwa zaidi ya miezi mitatu?	Hapana Ndiyo	0 1
	40. Je wewe ni mjumbe katika kundi lolote la waishio na UKIMWI wanaosaidia katika ufuasi mzuri wa dawa za ARV?	Hapana Ndiyo	0 1
	41. Je ni sababu zipi zimekufanya uache kuhudhuria kliniki ya CTC kama ilivyokuwa hapo awali?		
	42. Kwa uzoefu wako je unaona ni sababu gani zinawapelekea wengine pia kushindwa kuhudhuria kliniki za CTC kama ilivyokuwa hapo awali?		

