**ASSESSMENT OF THE FACTORS HINDERING RETENTION OF PEOPLE LIVING WITH HIV AND AIDS IN CARE SERVICES: A CASE STUDY OF CARE AND TREATMENT CENTRES IN KILOLO DISTRICT COUNCIL**

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**A DESERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE MASTERS DEGREE OF SOCIAL WORK**

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# CERTIFICATION

The undersigned certifies that has read and here by recommends for acceptance by the Open University of Tanzania a dissertation entitled, ***“Assessment of the Factors Hindering Retention of People Living with HIV AND AIDS in Care Services in Iringa Tanzania: A Case of care and Treatment Centers in Kilolo District Council***” in partial fulfillment of the requirements for the award of Masters Degree of Social Work.

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(Supervisor)

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**Date**

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# DECLARATION

I, **Issa Mohamed,** do hereby declare that this dissertation is my original work and it has not been presented and will never be presented to any other University for a similar or other degree award.

………………………..………

**Signature**

…………………………………

**Date**

# DEDICATION

I dedicate this work to my Family, Organization and colleagues for encouraging me throughout the duration of undertaking my studies with material and moral support.

# ACKNOWLEDGEMENT

First of all, I would like to give my sincere gratitude to the Almighty God for his free and unconditional gift of love, grace and life to accomplish my research in Kilolo district council. I thank my Director Mr. Aloyce Kwezi for giving me an opportunity to join further studies; I was provided with this chance despite of his being fully aware that I was highly needed by the organization.

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# ABSTRACT

The focus of this study was to assess the factors hindering the retention of people living with HIV/AIDS using Care and Treatment services as a case study in Kilolo District. Specifically, the study aimed to examine social factors, economic factors, health related factors and patient related factors as they influence retention. The study was qualitative using interview guide through the interviews to collect the data. Non probability sampling with purposive sampling techniques employed to obtain 60 respondents from Ilula. Thematic analysis used to analyze the data regarding the factors while descriptive statistics employed while analyzing the demographic characteristics of respondents. The study results indicate that patient, social, health systems and economic concerns affect patient retention in care particularly poor customer care, travel distance to ART centers, cost of transportation and high patient load with long waiting times at the clinic represented the greatest barrier to access treatment. In additional, HIV related- stigma and non-disclosure of HIV status to sexual partners and families are significant barriers. However, if the needs of patients are to be met, systems in health facilities need to be strengthened to reduce loss to follow up, increase adherence and promote long term retention.

**Keywords: *Factors Hindering Retention of People Living with HIV and AIDS in Care Services***

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# LIST OF ABBREVIATION AND ACRONYMS

AIDS Acquired Immune Deficiency Syndrome

AR Anti-Retro Viral

ART Anti-Retro Therapy

CTC Care and Treatment Centers

CD4 Cluster of Differentiation 4

CHAC Council HIV/AIDS Council Coordinators

CBHS Community Based Health Services

DACC District Aids Coordinator

DDPO District Data officer

DHIS District Health Information System

HIV Human Immunodeficiency Virus

KDC Kilolo District Council

KMO Keizer-Mayer-Olkin

MOH Ministry of Health and Social Welfare

NACP National Aids Control Program

PLWH People Living With HIV

SPSS Statistical Package for the Social Sciences

THMIS Tanzania Malaria Indicator Survey

UNAIDS United Nations Joint Program on HIV/AIDS

# CHAPTER ONE

# 1.0 INTRODUCTION AND BACKGROUND TO THE STUDY

## 1.1 Overview of the Study

Retention to the HIV and AIDS care service is very crucial to the people living with HIV and AIDS as they are required to be under Anti-Retro Therapy (ART) for their life time. This is so because it can help patients to avoid drug resistance which may end up to the opportunistic diseases and even HIV death related. The focus of this study was to assess the factors affecting the retention of people living with HIV/AIDS using Care and Treatment Centers as a case study~~;~~mainly, the study examined the factors affecting retention of people living with HIV/AIDS in the care and treatment services. In addressing the subject under study, this chapter presents the Background to the problem, Statement of the problem, objectives of the study, Research questions, and Significance of the study, Scope of the study and Definition of key terms of the study.

## 1.2 Background to the Study

It is widely agreed that significant progress has been made against HIV pandemic globally due to rapid scale-up of the provision of Antiretroviral Therapy (ART) through public health programs. For instance, in 2017, there were 19.6 million people living with HIV in Eastern and Southern Africa where by only 11.7 million people were accessing antiretroviral therapy (UNAIDS 2017). This is also supported by the study conducted by (Mayer, KH, 2011) on Multiple syndemic psychosocial factors are associated with reduced engagement in HIV care among a multinational, online sample of HIV-infected clients in Latin America. He revealed that over the past 15 years, there have been major advances in the development of effective antiretroviral treatments (ARTs) that can reduce morbidity and improve survival for patients infected with human immunodeficiency virus with regard to the progress made against HIV/AIDS globally. However, there are still challenges in retaining the patients in the care services provided in health care centers which can be influenced by other factors more than tracking system. A prerequisite to developing interventions to retain patients in care between testing and treatment is an understanding of where and when the patients are being lost.

Research on retention in pre-ART care is challenging, as it requires long periods of follow-up and consistent information systems that allow individuals to be tracked as they move in and out of care at multiple facilities. Furthermore, it is acknowledged that the poor and lack of consistent tracking system is the cause of the loss of patients in the care systems (Rosen and Fox, 2011). However, the poor tracking system is a one side factor thus it establishes doubt on why the patients are not successfully retained for the care services. The challenges in retaining people with HIV/AIDS in care and treatment centers are also reported in the other part of the world. For example, in a qualitative study conducted in urban Kenyans found that fear of taking medication on an empty stomach due to lack of food was cited widely as a reason for refusing to take antiretroviral, despite ART clinical eligibility and free access. From these experiences, individuals with low income in many parts of the world are prone of being lost due to failure in accessing health care services (Unge et al., 2010). It has also been reported that, India, being with massively with unemployed population and having a lower income, were both associated with incapability in accessing ART among HIV-infected individuals. In Tanzania, the report on the assessment of home based care service programs in Support of the Tanzanian HIV/AIDS response revealed that lack of transportation posed significant challenges in visiting all patients in order to provide the required services particularly to those residing far from the health centers (Ministry of Health and Social Welfare, 2013). This indicates that, with the lack of assured individuals and or household income, HIV/AIDS victims will not successfully attend clinic located in distant places for the purpose of getting care and other services. Again in the context of Tanzania, geographical landscape with transportation system requires household and or individual income capacity.

Ministry of Health and Social Welfare – MOH, (2013) in Tanzania acknowledged that, since 2010 there has been greater recognition of the difficulties in tracking and tracing patients who transfers from one clinic to another, or who are lost to follow up. Ahonkhai et al (2012) on her study on “Not All Are Lost” she revealed the problem of lack of follow up despite of the existence of the efforts made by the South African State and suggests for an alternative motivational effort to improve care and services retention status. Although it was advised that, there is still an urgent need for further improvement in the retention of patients in the Care and Treatment Centre the report did not explain the reasons behind the increasing rate of loss to follow up. More importantly, facilities need to ensure the presence of counseling is effective to ensure the retention of patients. In addition, methods to ensure adequate tracking mechanisms are needed for the patients who did not keep appointments. Furthermore, it has to be remembered that, without retention of the HIV patients in the clinics the loss of follow up will increase the rate morbidity and mortality among patients with HIV/AIDS as well as new infections could increase (UNAIDS, 2017). With this note, it is imperative to know factors hindering retention of people living with HIV and Aids in care and treatment centers, in local context specifically within Ilula Ward in Kilolo District council.

## 1.3 Statement of the Problem

There is a significant progress worldwide against HIV/AIDS pandemic in terms of access to the required services such as care and treatment. However, there are challenges in retaining the people with HIV/AIDS in the provision of services due to ongoing loss to follow up of the patients living with HIV/AIDS. In Tanzania, HIV reports there were 1.4 million people living with HIV/AIDS by 2016 and only 440,000 people enrolled to ART.

However, among them 98,448 people were reported to have dropped out from care and treatment services (DHIS 2, 2019). In Kilolo District during the financial year 2018/19 the total of 57,768 patients were enrolled in ART but 24,204 dropped from ART. Specifically, Ilula Ward had, 29, 052 patients enrolled in ART whereas a total of 12,070 patients dropped out from care and treatment in the year 2018-2019 (DHIS 2, 2019). The reasons for the drop out are inadequately provided. The most cited reasons like poor tracking systems, mobility of the patient, education, health insurance, and transportation costs cannot be generalized. This study focused on multidimensionality of the factors hindering retention of people living with HIV and AIDSin Care and Treatment Centers in Ilula Ward.

## 1.4 Objectives of the Study

## 1.4 .1 General Objective of the Study

This study aimed to assessing the factors hindering the retention of people living with HIV/AIDS in care and treatment centers services in Kilolo District Council.

## 1.4.2 Specific Objectives

1. To identify the economic factors hinderingretention of people with HIV and AIDS in the care services in Ilula Ward in Kilolo district council.
2. To examine social factors hinderingretention of people with HIV and AIDS in the care services in Ilula Ward in Kilolo district council.
3. To analyze health facility based factors hindering retention of people with HIV and AIDS in the care services in Ilula Ward in Kilolo district council.
4. To examine Patient related factors hinderingretention of people with HIV and AIDS in the care services in Ilula Ward in Kilolo district council.

## 1.5 Research Questions

1. What are the economic factors hindering the retention of people with HIV/AIDS in care and treatment services in Ilula Ward in Kilolo district council?
2. What are the social factors hinderingthe retention of people with HIV/AIDS in care and treatment services in Ilula Ward in Kilolo district council?
3. How health facilities do based factors hindering retention of people with HIV and AIDS in the care services in Ilula Ward in Kilolo district council?
4. What are the Patients related factors hindering retention of people with HIV and AIDS in the care services in Ilula Ward in Kilolo district council?

## 1.6 Significance of the Study

The findings of the proposed study are expected to be of theoretical and practical significance. Theoretically, the study is expected to make a paramount contribution on how to retain people living with HIV and AIDs in Care and Treatment Centers by providing insights into factors hindering their retentions. This is because the significance of the proposed study is derived from the importance of retention of patients as the backbone of care and treatment centers performance. It is envisaged that the study will boost the interest of health centers care professionals in patients’ retention as a tool for achieving and sustaining these care and treatment centers. Further still, the current study will be cited as reference for greater insights into the major determinants of patients’ retention in Care and Treatment Centers.

The study has practical implications for administrators and other professionals in health care centers, firstly, findings will be resourceful for other researchers and scholars, as it forms a basis for academic discussions on various aspects of determinants of patients’ retentions adopted by other health care and treatment centers. Moreover, because empirical research on determinants of patients’ retentions in health care centers is limited in both quantity and quality, the proposed study will make a valuable addition to the body of knowledge in Tanzania. The findings of this study will also act as a resource for other researchers who intend to replicate similar studies in Tanzania. Also social workers will be informed on what affects people living with HIV and AIDS to attend care centre, and work on the issues raised so as to reduce concerns like waiting time, customer care and long queue and in turn will counsel the patients and their relatives to make sure that they support these patients The findings of the current study can help the government and policy makers in formulating policies aimed at improving services in health care and treatment centers; this also can improve performance of many centers in Tanzania. Therefore, the study is bridging the identified knowledge gap by assessing factors hinderingretention of people living with HIV and AIDS in health care and treatment centers in Tanzania.

## 1.7 Scope of the Study

This study is limited to the retention of people living with HIV/AIDS particularly on the factors hindering the retention on the care services. In undertaking the study, Kilolo District is taken as a case study whereby the sample of the study from three selected health facilities used approach with purposeful sampling in data collection.

## 1.8 Definition of Key Terms

## 1.8.1 Patient Retention

Refers to the successful observation of the scheduled healthcare attendance by the patient for the purpose of monitoring the condition of people with HIV/AIDS. Retention in care as the ability to adhere to critical aspects of care, such as attending regular follow up appointments, scheduled laboratory tests and other monitoring activities as prescribed by the health care provider (Fox & Rosen, 2010; Geng et al., 2010). In this current study retention was determined by a patient attending the last scheduled follow up appointment.

**1.8.2 Patient Drop Out**

Is the discontinuation of ART by patients through death, loss to follow-up, and stopping ARV medications while remaining in care. Drop out also include patients who are alive, have stopped ART due to a variety of reasons (Fox & Rosen, 2010). This is true especially in ART programs that lack capacity to trace and monitor patients outside the confinements of the clinic (Musheke et al., 2012).

**1.8.3 Antiretroviral Therapy ART**

**ART:** Antiretroviral therapy (*ART*) Antiretroviral therapy (*ART*): Treatment that suppresses or stops a retrovirus. One of the retrovirus is the human immunodeficiency virus (HIV) that causes *AIDS* (Amico, 2011).

**1.8.4 HIV and AIDs**

*HIV and AIDS: HIV* stands for human immunodeficiency virus. It harms your immune system by destroying the white blood cells that fight infection. This puts you at risk for serious infections and certain cancers. AIDS stands for acquired immunodeficiency syndrome. It is the final stage of infection with HIV(Tuller, Bangsberg, Senkungu, 2009).

**1.8.5 Care Services**

**Care services:** a service that provides [medical](https://www.collinsdictionary.com/dictionary/english/medical) [treatment](https://www.collinsdictionary.com/dictionary/english/treatment) and [care](https://www.collinsdictionary.com/dictionary/english/care) to the public or to a particular group. It is an entity that provides inpatient or outpatient testing or treatment of human disease or dysfunction; dispensing of drugs or medical devices for treating human disease or dysfunction. A procedure performed on a person for diagnosing or treating a disease (Fox & Rosen, 2010).

# CHAPTER TWO

# 2.0 LITERATURE REVIEW

## 2.1 Introduction

This Chapter mainly presents and comprehensively discusses three key aspects namely: theoretical literature review, empirical literature review and conceptual framework. Theoretical literature review provides scientific definitions of the major concepts describing the phenomenon being studied while empirical literature describes what has been done to solve or address the contradicting relationship in the phenomenon. Conceptual framework summarizes the major (independent and intervening) and (dependent) variables under study in a graphical structure so as to observe the presumed or predicted outcome.

## 2.2 Theoretical Review

The purpose of this section is to concretely examine the theory that has accumulated in regard to an issue, concept, theory, or phenomena. The theoretical literature review helps establish what theories already exist, the relationship between them, to what degree the existing theories have been investigated, and to develop new hypotheses to be tested. Often, this form is used to help establish a lack of appropriate theories or reveal that current theories are inadequate for explaining new or emerging research problems. The unit of analysis can focus on a theoretical concept or a whole theory or framework (Fink 2005). The literatures have been trying to explain theories related to the effectiveness of Anti-Retro Viral Therapy as the means to improve the lives of the People living with HIV and AIDS (PLWHAIDS). However, those literatures concentrated on the importance of behavior change and motivation as the catalyst towards accessing care and treatment services. Therefore, in order to explain the use of ART to the People living with HIV and AIDS (PLWHAIDS)AIDS the Social Cognitive theory and Information Motivational model were used to explain the role of behavior change and motivational environment as the means to increase ART enrolment and service use.

## 2.2.2 Social Cognitive Theory

The theory of behavior change has major implications in the health promotion status (Bandura, 1998). Among others, the theory was employed by Smith (2013) in the study of HIV care utilization: A theory - Based Approach to Retention in Care postulates a multifaceted causal structure in the regulation of human motivation and actions. The theory suggests that knowledge of health risks and benefits are pre requisite for the changes to occur. In this theory, it is believed that behavior is affected by the expected outcomes which may be positive or negative.

In this theory therefore, knowledge about the outcomes and the risks encountering the human being lead to the change in behavior. In the course of this study change of behavior is an important component in the retention of people living with HIV/AIDS in the care services which is the focus of this study. The moment people living with HIV/AIDS get awareness on the health risk of dropping out from the health services contribute to the change of behavior towards retention to the care services. In the view of this study, retention and or drop out is largely driven by the behavior developed by the patients and therefore, the social cognitive theory plays an important role in accomplishing the study.

**2.2.2.1 Significance of Social Cognitive Theory to the Study**

Social Cognitive Theory describes the influence of individual experiences, the actions of others, and environmental factors on individual health behaviors. This relates with the current study as the actions of health officers and social workers may influence the behaviors of the patients to attend or not to attend the care centre for them to access the services. If they are mistreated they will opt not to attend the care centers. Also, for the case of environment this means that if the hospital location is far away from their homes, and lack of enough health professionals and drugs, patients will opt not to go and vice versa is true.

## 2.2.3 Information Motivation Behavioral Skills Theory

Information Motivation behavior; This theory was derived from the work by Amico (2011). The model was also applied in the other research work conducted by Smith et al (2013) on understanding the behavioral determinants of retention on HIV care. The theory suggests that, understanding behavioral determinants results to the reduction of HIV/AIDS risks. Using the theory, complex health behaviors including HIV prevention can be dealt successfully. The model focuses on three behavioral determinants which are information, motivation and behavioral skills. In this theory information is said to be an important component as it guides the individual’s decisions. It is therefore necessary that the information gained by the individual must be accurate and timely. Motivation shapes the individual’s attitudes and beliefs. On the other hand, behavioral skills as described in the model establishes objective skills and perceived self-efficacy to enact the behavior overtime and across different situations. In terms of patients’ retention to care services which is the focus of this study, this model clearly elaborates the important aspects which are significantly applicable. As human being subject to various situations in order to respond, the elements explained in this theory such as information, motivation and behavioral skills contribute positively or negatively to the individual reactions. In the course of this study, it is assumed that the retention of people with HIV/AIDS in care services depends on the type of information and the patients hold. It can be considered that, if individuals are well informed about HIV/AIDS care benefits and procedures they can likely be motivated to attend care within the recommended intervals and timeframe. The same individual who are informed and motivated are in the good position to build a skilled behavior which will result to a permanent retention for the prescribed period for the care services. It is therefore obvious that, weakness in information, motivation and behavioral skills will result to poor retention in cares which will likely result to poor viral suppression and other health outcomes.

## 2.3 Empirical Review

Empirical research is a [research](https://en.wikipedia.org/wiki/Research) using [empirical evidence](https://en.wikipedia.org/wiki/Empirical_evidence). It is a way of gaining knowledge evidence by means of direct and indirect  [observation](https://en.wikipedia.org/wiki/Observation)  or  [experience](https://en.wikipedia.org/wiki/Experience). [Empiricism](https://en.wikipedia.org/wiki/Empiricism) values such research more than other kinds. Empirical evidence (the record of one's direct observations or experiences) can be analyzed quantitatively or [qualitatively.](https://en.wikipedia.org/wiki/Qualitative_research) Quantifying the evidence or making sense of it in qualitative form, a researcher can answer empirical questions, which should be clearly defined and answerable with the evidence collected (usually called [data](https://en.wikipedia.org/wiki/Data)). Research design varies by field and by the question being investigated. Many researchers combine qualitative and quantitative forms of analysis to better answer questions which cannot be studied in laboratory settings, particularly in the social sciences and in education (Kothari, 2004).

## 2.3.1 Economic Related Hindering Retention of people with HIV/AIDS in Care and Services

The study conducted in Malawi indicated that, access to care services incurs several costs depending on geographical locations. It was revealed that, some patients were getting services in the district hospital and others in local health centers. In this circumstance, the mode of transport to a significant degree determines the state of patients’ retention to care services (Pinto et al, 2013). Getting care service in distant clinic centers increases costs not only for the patients but also the costs for the guardians or helpers who accompany the patients in each visit. This situation not only discourages the patients but also the guardians which ultimately lead to loss to follow up for the patients.

The other study by Muula (2006) revealed that, living far from treatment centers with high transport costs were anticipated to be barrier to care to the people with HIV/AIDS. This is common to most people residing in rural area where the health centers with the service are far from the people’s living places. It is from these circumstances, there is all possibility of losing patients in the course providing care services in most localities. Moreover, a study on “Retention of HIV Positive Persons in Antiretroviral Therapy Programs in Post-Conflict Northern Uganda-Baseline Survey of 17 Health Units” done in South Africa by Miller et al, (2010) reported that, the transport cost, disclosure of HIV status and stigma at work place, beliefs, living far from health facility, taking alcohol, patients self-transfer to other clinics without documentation, misconception about ARVs and having wrong knowledge about ARVs to be the reasons for the loss of follow up visits for HIV patients. In this situation retention of patient for care services is a difficult one. As the reason being multiple, critical analysis is important for the purpose of establishing mechanisms of retaining patients for care services. In a qualitative study in Uganda, individuals receiving free antiretroviral medications often had to choose between using their limited income on paying for transportation to the clinic versus being able to adequately feed themselves and their children (Tuller, Bangsberg, Senkungu, 2009). It is unquestionable that nutritious food has important role in building and protecting the body. Food insecurity was also associated with lower CD4 cell counts among HIV infected individuals (Weiser, Bangsberg, Keeled, 2009). From these observations, food security as an important component in maintaining health is subject to individual and household income.

Although patient can attend the clinic for health care food insecurity is the other challenge in protecting and building the healthier body. This component of food insecurity which has direct relationship with the health of the patients contributes to the loss to the follow up because patients can be seeking food instead of attending the clinic. The access to food is significantly related to the income of individual and the household at large. This seems to the problem to most patients with low income. In the situation like these ones, most patients would possibly fall off in accessing to care and treatment services hence failure of being retained. In the literature reviewed on the subject, the revealed concerns on retention are not sufficient and synonymous among societies. Although social, facility, economic factors play a major role in patients’ retention they must be analyzed on the base of local factors of the area concerned.

## 2.3.2 Social Factors Hindering Retention in Care Services for People Living with HIV/AIDS

Roura et al., (2009) revealed that, social factors that influence the retention in care among others include unfriendly social support, relationship with marital partners, family members support and peers. These situations in one way or another affects the individual’s behavior and actions. It has also been experienced that, partners do not disclose their health status to their spouses or other family members for the fear of marriage interruption. From these situations, individuals are discouraged of accessing services and other protection mechanisms. Further, Musheke et al., (2012) added that, HIV/AIDS related stigma is a serious obstacle to a working retention of people in the care systems. Individuals are reported to be rejected, denied, and socially distanced from other community members.

It is from this experience the rate of retention always fails to reach the targeted predetermined levels. In the other circumstance, a study from Malawi shows that stigma leads to non-retention in up to 25% of patients on ART (Mc Guire et al., 2010). If universal access to treatment is to be achieved, effective strategies addressing stigma and discrimination must be developed. This can positively be done through stronger community involvement in the process of stigma analysis and recommendations. From these scenarios, one has to look at retention beyond a mere look up of matters in multiplicity. Of more vital, social factors are inefficient when traced from outside view but brings more meaningful when addressed from individual point of view.

## 2.3.3 Facility based factors Hindering Retention of People with HIV/AIDS in Care and Services

Poor access to health facility significantly contributes to patient’s dropout in accessing the required services particularly long distance to the health facility. For instance, a study in Uganda reports that long distances to ART centers were considered serious obstacles to care and led to poor retention of patients on ART program (Tuller et al., 2010). From this experience it can be agreed that the easier access to health facility there are great possibility for the people to be retained in the care and other health services. It has also been reported that the shortage of skilful personnel in Sub Saharan Africa is among drivers for the poor retention for people with HIV/AIDS in care services (Lambdin et al., 2011).

Tanzania as among the sub Saharan Africa cannot be isolated from these experiences because there is no doubt that most developing countries experience shortage of personnel in most demanding sectors such as health. The shortage of personnel may result in long waiting for the patients at the service providing places which ultimately results to patients’ frustration and being discouraged of seeking services resulting to poor retention in the care services (Callaghan, Ford & Schneider, 2010). It is further argued that, most health facilities suffer from the shortage of mentors in the course of service provision. The lack of mentors contributes to loss to follow up in the provision of services because the patients require the mentoring services in order to guide and instruct them in the course of services provision. Through mentoring, the patients build confidence in the hard time they are passing through. Also, in most health facilities, counseling is insufficiently provided due to the shortage of professional counselors. Because of this situation, most patients drop out in the course of accessing services. In some facilities, the volunteers are used as counselors although they are not paid allowances in order to perform their duties successfully. In the study done by Ohene et al., (2013) in Ghana, was argued that, delays in laboratory results discourages the patients in attending clinics for the services. Delays to HIV patients are the discouraging situation. Further, Ohene et al argued that, proper documentation helps in managing the patients accordingly. However, this is rarely done in most health centers. Through proper documentation, health providers are in the good position of managing patients’ data as required. These situations contribute to poor follow up hence failure in noticing the retention status.

## 2.3.4 Patient Related Factors Hindering Retention of People with HIV/AIDS in Care and Service

Some HIV and AIDS patient drop out from care especially in taking antiretroviral drugs due to side effect they encounter for. According to Musheke et al., (2012) Patients consider the side effects lead to unfavorable condition to their health and disturb their normal activities so they decide to discontinue with treatment. Other patients decide to quit from HIV and AIDS services when they feel they have no more complication in their body. Musheke et al., (2012) argue that a sense of wellbeing in patients receiving antiretroviral treatment decreases motivation to continue on treatment. There is need for intensive counseling at each follow up visit in order to improve retention in care. Wasti et al (2012) said Patients’ beliefs, knowledge, and expectations regarding treatment strongly influence their medical decision-making; findings show that some participants questioned the efficacy of ART. PLWH who believed in the efficacy of ART are more likely to adhere and both educations level of PLWH and educational programs which affect adherence. Providing better information about HIV/AIDS reduces both fear and ignorance so that patients maintain their medication better.

## 2.3.5 Description of the Variables

Economic factors: Refers to all cost incurred in order to access HIV and AIIDS care services, these include the transportation costs, drugs and testing costs, foods and basic needs (Pinto et al, 2013). Social factors: Are the things that influence community and can affecting life style; these include stigmatization, discrimination, psycho social support and religious belief (Musheke et al. 2012).

Patient related factors: these are the determinants which are based on individual decisions. It includes perception on the side effects of ART, use of alcohol, and tiredness due to long time uptake of ARTs (Ohene et al., (2013). Health facility based factors: These are factors that are associated with the facility environment that hinder retention. These include customer care, availability of drugs, privacy, availability of health workers and service waiting time

# CHAPTER THREE

# 3.0 RESEARCH METHODOLOGY

## 3.1 Introduction

Research typically refers to the techniques used while conducting a research (Hair et al, 2006) and these include; data collection instruments such as questionnaires, interviews or observations as well as sampling procedures and statistical techniques for organizing and interpreting unstructured data (Bryman, 2007).This chapter spells out the research approach and seeks to establish sound reasoning in linking the steps employed to answer the research questions and to achieve the objectives of the research and further, sampling methods and data analysis were discussed. Issues of confidentiality, validity and reliability of the study are all addressed therefore; the chapter generally discusses the following: research design, approach, study area, population sample, data types and sources, types of measurements, population and sampling design, data collection instruments and pilot testing. Others include data collection methods, validity, reliability, ethical issues and finally the data analysis plan.

## 3.2 Research Design

In this study, descriptive research design employed. Case study used because of its relevance in examining the state of retention for people living with HIV and AIDS in the care services. Through this design adequate and relevant information concerning the study based on the actual picture and opinion of the participants were collected; also the case study is helpful in looking at phenomenon sufficiently for the purpose of realizing the objectives of the study. Through this design, data was successfully managed concerning the phenomenon under study. Further, the descriptive statistical design used in collecting qualitative data particularly in examining factors hinderingretention of patients in care centre.

## 3.3 Area of the Study

Kilolo District Council is located at the north eastern end of Iringa Region, about 37 kms from the regional headquarters. It also lies adjacent to the eastern borders of Iringa Rural and Iringa Municipal Council. The District Council, however shares borders with Mpwapwa District (Dodoma Region) in the North, Kilosa district (Morogoro Region) in the North East, Kilombero District (Morogoro Region) on the East, while Mufindi District is on the south with Iringa Rural District on the west. In terms of international identification, the district lies between 70 and 8030’ south of the Equator and between 340 and 370 east of Greenwich with a total surface area of 6,804 sq. kms.

The mid land zone lies on the rift valley of Mazombe plains and portion of northern part of the district especially Image ward, covered with sand clay soils. The zone is characterized by undulating topography and plateau at an altitude of between 1200 and 1600 meters above sea level. It has moderate temperatures ranging between 150– 200 centigrade and characterized with moderate rainfall. Agriculture in this zone depends mainly on rain and involves the cultivation of maize, sweet potatoes, sunflower, onions, tomatoes, cowpeas, beans and tropical fruits such as mangoes, guava and pawpaw. Due to its temperatures the greatest part of the area is used for grazing cattle and dairy farming, sheep, pigs, goats and chicken.

**3.3.1 Health Care Services**

Though the residents of Kilolo district are said to have relatively good accessibility to social services like health, education and water; the HIV/AIDS pandemic is among the diseases that have a negative impact to morbidity and mortality but the orphaned and widowed rates recorded in the district at 1.82 percent and 5.6 percent, respectively are not the highest in the region. The health situation of the Kilolo people can also be observed through other proxy heath indictors in Table 2.4 which include:

Infant Mortality Rate (103 per 1,000 infants), Children Under Five Years Mortality Rate (170 per 1,000 U5 children), HIV/AIDS prevalence rate (12.4 percent), Doctor/Population Ratio (27,266 people per doctor) and Hospital Bed/Population Ratio (1,124 patients per bed). Surprising enough, the Health Department of Kilolo district put their current IMR at 5 which is above the WHO rate of 50 for many districts. The most populous ward was Nyalumbu with 15,306 persons (7 percent) followed by Ukumbi at 12,912 (5.9 percent) and Lugalo at 12,359 (5.7 percent).

The least populous ward according to the2012 census was Ngángánge having 4,123 persons (1.9 percent). The uneven distribution of Kilolo residents is mostly influenced by the availability of natural resources including arable land that is suitable for cultivation and irrigation and also accessibility of infrastructure. Table 1.9a gives the population distribution by ward according to the 2012 Population Censuses.

|  |
| --- |
| kilolo map 2 |

Figure 3.1: Map of Kilolo District Council showing Population Distribution by Ward, 2012 Census

Source: National Bureau of Statistics (2012 Census data)

Table 3.1: The 2012 Census Population

|  |  |
| --- | --- |
| **Ward** | **Population, 2012** |
| **Male** | **Female** | **Total** |
| Image | 4,404 | 4,776 | 9,180 |
| Irole | 5,734 | 6,412 | 12,146 |
| Ilula | 5,264 | 5,845 | 11,109 |
| Uhambingeto | 5,100 | 5,227 | 10,327 |
| Lugalo | 6,004 | 6,355 | 12,359 |
| Nyalumbu | 7,406 | 7,900 | 15,306 |
| Mlafu | 3,190 | 3,196 | 6,386 |
| Ibumu | 3,252 | 3,429 | 6,681 |
| Mazombe Division | 40,354 | 43,140 | 83,494 |
| Udekwa | 2,949 | 2,854 | 5,803 |
| Mahenge | 5,074 | 4,965 | 10,039 |
| RuahaMbuyuni | 6,144 | 6,007 | 12,151 |
| Mahenge Division | 14,167 | 13,826 | 27,993 |
| Mtitu | 5,558 | 5,770 | 11,328 |
| Dabaga | 3,700 | 4,087 | 7,787 |
| Ukumbi | 6,352 | 6,560 | 12,912 |
| Ukwega | 5,913 | 6,282 | 12,195 |
| Bomalang'ombe | 5,358 | 5,955 | 11,313 |
| Idete | 3,791 | 4,268 | 8,059 |
| Masisiwe | 4,729 | 5,324 | 10,053 |
| Ng'uruhe | 5,339 | 5,673 | 11,012 |
| Ng'ang'ange | 1,942 | 2,181 | 4,123 |
| Ihimbo | 4,978 | 5,234 | 10,212 |
| Kimala | 3,675 | 3,974 | 7,649 |
| Kilolo Division | 51,335 | 55,308 | 106,643 |
| Total District | 105,856 | 112,274 | 218,130 |

Source: NBS, 2012 Census General Report.

The study was conducted in Kilolo District Council specifically at Ilula ward as it is among the Districts with rural population characterized by few HIV and AIDS care service centers. The District on the other hand is within a region (Iringa region) with the high HIV prevalence of 11.3% which is higher than national prevalence of 5.1% (THIS, 2016). For this case it is obvious that the District has high number of people living with HIV and AIDS who are enrolled in Care and Treatment Centers. In the course of data collection, Ilula hospital was taken as unit of analysis.

## 3.4 Study Population

The study population was people living with HIV and AIDS who dropped out from care services. The patient with HIV/AIDS still receiving care services, CTC service providers and district AIDS coordinators. This population is used because they are the one who have information on the situation affecting retention in HIV/AIDS care services. Using this population, sufficient information on the retention of people living with HIV/AIDS in the course of accessing care services was collected.

## 3.5 Sampling Techniques

Sampling technique is a definite plan for obtaining sample from a given population. Kothari (2004) refers sampling technique as a procedure that the researcher would adopt to select items for the sample. Sampling technique lay down the number of items to be included in the sample. Marko et al., (2014) notes that, there are two major goals that sampling can achieve. A sample is selected because in most cases it is rarely possible to cover all the individual elements comprising a population of interest due to the need for the possessing the knowledge on competent care and services and other reasons. The choice of every target population or category of respondents for this study was purposive basing on the type of information or themes or perspectives required on the study topic. The purposive sampling technique was therefore, used in this study in selecting an ideal and manageable size of respondents from both categories without biases and ensuring that all respondents have equal probable chance of participation in the study*.*

## 3.6 Sample Size

It is not possible to deal with the whole population of the study; therefore, the segment was selected to represent the rest. This study constitutes a sample of all participants (60) who were providing the required information. The choice of this sample considers the nature of the study which is qualitative. Since the population is small the researcher decides to use census method where all the population studied. The selected sample size is manageable for the successful collection and analysis of data as required for the fulfillment of the research objectives.

Generally, the sample sizes used in qualitative research are not justified (Marshall et al, 2013). There are no well-established published guidelines to allow formal estimation of sample size for qualitative research because qualitative studies generally do not aim to estimate magnitudes and to generalize a larger population, rather to evaluate patterns in a data set (how and why) (Pertti, 2010).There was a need for a researcher to ensure there is enough, but not too much data. Robert (2005) suggests samples of 20 and 30 respondents whereas Mason (2010) suggests a sample of 25-30 respondents. The researcher decided to use a small sample because the goal of qualitative research is to describe the phenomenon of interest and address the research questions. Apart from the small number that characterizes qualitative research, there is no specific answer to how many participants a researcher should take as a sample size (Creswell, 2013). In line with the above facts a saturation rule has been applied in this study. Saturation occurs when adding more participants to the study does not result in additional perspectives or information (Denny 2009; Sparkes et al. 2011). Charmaz (2006) suggested that you stop collecting data when the categories (or themes) are saturated; when gathering fresh data no longer sparks new insights or reveals new properties. Glaser and Strauss (1967) recommend the concept of saturation for achieving an appropriate sample size in qualitative studies.

Using the saturation rule and lack of common stand among authors in a qualitative research, the researcher extended to select 80 units in sample that met the criteria of time, resources and saturation for this study. The sample for this study comes from two main categories of population. The first category of sample participants was comprised of 20 health providers and 60 patients who get services in the centers within the district. The selection and decision on the involvement of 60 patients based on their availability during the study, readiness and willingness to participate in the study and achievement of data saturation (O’Reilly & Parker, 2012, Walker, 2012).

**Table 3.2 The Distribution of Sample**

|  |  |
| --- | --- |
| **Category** | **Number of Respondents** |
| Health provider | 20 |
| patients | 60 |
| **Total**  | **80** |

Source: Field Data (2019)

## 3.7 Data Sources

Data in this study was collected from both primary and secondary sources. This is because multiple sources are helpful in collecting comprehensive information concerning a phenomenon (Kothari, 2004). Primary data were collected from the participants particularly those who were getting care services from the care and treatment centers and service providers. Secondary data were collected from various reports indicating patient’s attendance in health centers for the care services.

## 3.8 Data Collection Methods

This study employed the combination of data collection methods namely, interview and documentary review. All these methods were used in order to obtain the detailed information in the course of the study.

## 3.8.2 Interview

Interview was used for the purpose of soliciting information, views and opinions mostly collected from the population which could not be assessed through other techniques. In the course of interviewing, face to face verbal communication between researchers and the health service providers and coordinators were employed through open-ended interview. The researcher had a set of themes identified from the data and some key questions to be covered. The interviewer commences with a set of interview themes, but the order of the questions may vary depending on the context of the research setting, in this study, the researcher employed the in-depth interview method with open-ended questions for patients, health workers and coordinators. The researcher conducted face to face and telephone interviews with participants. This method was used by the researcher because it provided the required information, attitudes and emotions of the patients. It was also useful in obtaining information that cannot be obtained by other methods. It also facilitated respondents’ perception on the service provided by the centre.

## 3.8.3 Documentary Review

Documentary review method was used in order to collect some information concerning the study. The documents reviewed are those carrying the information on the patient’s attendance in the service providing centers. Also the service providing reports on the progress of the whole process of service provision are among the reports which were reviewed. In this study the researcher used the documentary review which included the review of attendance register books, periodical reports, and individual patients’ files in order to check the history of the patients on attending the centre and taking of ART.

## 3.9 Data Processing and Analysis

In this study the researcher used qualitative research technique in data analysis beginning by identifying themes in the data and relationships between the themes. Analysis of themes is a method for identifying, analyzing and reporting themes within data (Virginia Braun and Victoria Clarke, 2006). The analysis of data proceeded hand in hand with data collection and the write-up of findings (Creswell, 2013). The researcher focused in on some of data and disregarding other parts of it. Not all documentary information could be used in the study. The researcher aggregated data into small number of themes (Creswell, 2013).

Table 3.3 Established Themes

|  |  |  |
| --- | --- | --- |
|  | **Main themes** | **Sub themes** |
| 1. | Economic factors | * Payment associated with services
* Transportation costs
* Cost of food and drinks
 |
| 2 | Social factors | * Community and family support
* Stigmatization
* Religious belief
* Traditional medicine
 |
| 3 | Health related factors | * Availability of drugs
* Customer care
* Waiting time
* Privacy
* Number of service providers
 |
| 4 | Patient related factors | * Patients perceptions
* Alcoholism
* Long term drug consumption
 |

Source: Field Data (2019)

The above method enables both descriptive and in-depth analysis of data due to its flexibility. The researcher began by identifying themes in the data and relationships between the themes. The researcher analyzed data in the form of logical statements and arguments. Qualitative research technique helped the researcher to analyze the findings of the study concerned. The researcher analyzed data by using qualitative computer data analysis software called Statistical Package for Social Science (SPSS V.20). This software was used because it is the common available and frequently used software by students to process academic data. Information was arranged in themes, coded and processed in terms of frequencies, percentages, tables, charts and histograms. As such, allowed the data to speak for itself in the sense that themes were identified inductively from the data and therefore allowed to emerge naturally from the same data. Thematic groupings were developed based on the initial codes after which the themes were refined and defined so as to come up with the final themes that were used.

## 3.10 Trustworthiness in Qualitative Research

**3.10.1 Credibility**

Credibility is the how confident the qualitative researcher is in the truth of the research study’s findings.  The method is used by qualitative researchers to establish trustworthiness by examining the data, data analysis and conclusions to see whether or not the study is correct and accurate.  For qualitative researchers, credibility is a method that includes researchers taking on various activities that increase probability so that there will be trustworthy research findings (Lincoln & Guba, 1995).

Credibility contributes to a belief in the trustworthiness of data through the following attributes: a) prolonged engagement, b) persistent observation, c) triangulation, d) referential adequacy e) peer debriefing and f) member checks (Krefting, 1990 & 1991). In this study the researcher used more than one method of data collection. Such methods included in-depth interviewing, and documentary reviews; during data collection involving different categories of participants or sample populations by asking the same research questions with all research respondents and colleague to look over the study to ensure that the research study findings are credible and determine whether the results seem to align to the dataLui, L., & Standing, L. (1989).

* + 1. **Transferability**

Another method used by qualitative researchers to establish trustworthiness is transferability. In qualitative studies, transferability means the method against which applicability of qualitative research study findings to other research contexts; including similar situations, populations, phenomenon and settings is assessed (Guba, 1981 & 1985). This method is used by qualitative researchers to provide a detailed description of the study problem, study site, study participants and procedures used in data collection to enable other researchers to assess whether or not the study findings can be a good match or representative of others and makes a sense to generalize about the subject of the research (Sandelowski, 1986). In this study, the researcher used a case study design and selected Ilula health care centers inKilolo District to represent all other CTC in the country. The researcher has given a detailed description of the study problem, study site and of categories of study participants and the significance of their participation in the study.

* + 1. **Confirmability**

Confirmability in Qualitative Research means the degree to which the research outcomes could be confirmed or collaborated by other researchers (Baxter, &Eyles, (1997). It is the degree of neutrality in the research study findings, where the findings are based on and accurately portrays participants’ responses and not any potential bias or personal motives of the researcher (Sandelowski, 1986). Confirmability involves making sure that the researcher bias does not skew the interpretation of what the research participants said to fit a certain subject matter (Lincoln & Guba, 1985). Qualitative researchers can provide an audit trail, highlighting every step of data analysis that was made in order to provide a rationale for the decisions made so as to establish confirmability of research results. In this study, the researcher derived the data from the participants’ responses and presented the same in the analysis but not otherwise. To establish confirmability in this study, the researcher preserved the research materials and stored the manually collected information from respondents and other participants as an assurance that the researcher has accurately translated the participants’ viewpoints into data.

## 3.11 Ethical Consideration

Ethical consideration is part of the research works, and cannot be avoided (Bryman, 2004). The major aspects to consider ensuring adherence to ethical rules includes; voluntary participation, the right to privacy, freedom and anonymity and confidentiality (Bless and Higson-Smith, 2000). Observation of research ethics helps to protect the rights of the research participants, develop a sense of trust with them, and promote the integrity of the research (Israel and Hay, 2006). As the way of observing ethics in research, several attempts will be taken.

According to Creswell (2009) and Kombo and Tromp (2006), it is mandatory that research participants get informed before they are approached for data collection. To comply with this, the respondents were informed before data collection through the use of consent letters. Consent letters contain important information about this particular research, and the importance of their participation in the study. The aim is to seek their consent, ensure voluntary participation and provision of information, as well as giving them free room to withdraw from the research participation any time they wished to (Creswell, 2009; Kombo and Tromp, 2006). Creswell (2009) and Kombo and Tromp (2006) insist on anonymity and confidentiality in research study. In this study, the names of the respondents in the entire study were kept anonymous. This reduces bias and the possibility of the participants being recognized. Additionally, the data collected from the respondents kept confidential and erased after their use.

# CHAPTER FOUR

# 4.0 PRESENTATION, ANALYSIS AND INTERPRETATION OF FINDINGS

## 4.1 Introduction

This chapter deals with data presentation, analysis and interpretation of findings from this study. This chapter presents the research findings based on the study objectives. These objectives include examining economic factors, social factors, health facility based factors and patients related factors affecting retention of people with HIV and AIDS in the care services specifically within Ilula ward. Qualitative findings are presented based on themes. Descriptive statistics gave the demographic data and results on the factors affecting retention of people with HIV and AIDs in care and treatment centers.

The major findings of this study have been summarized at the end of this chapter. The purpose of analyzing data is to obtain usable and useful information that could describe and summarize the data, identify the relationships between variables, compare variables, identify the differences between the variables and forecast the outcomes, while interpretation makes the data meaningful in relation to the research problem studied and be able to draw conclusions Sutton, J., & Austin, Z. (2015).). The research questions of the study which the analysis attempted to answer were as follows:

1. What are the economic factors hindering retention of people with HIV/AIDS in care and treatment services in Ilula Ward in Kilolo district council?
2. What are the social factors hindering retention of people with HIV/AIDS in care and treatment services in Ilula Ward in Kilolo district council?
3. How health based facilities hindering retention of people with HIV and AIDS in the care services in Ilula Ward in Kilolo district council?
4. What are the Patients related factors hindering retention of people with HIV and AIDS in the care services in Ilula Ward in Kilolo district council?

##

## 4.2 Demographic Characteristics

## 4.2.1 Sex of Respondents

The study involved a sample of 60(100%) respondents who filled the questionnaires. Among them 19 (32.5%) of total respondents were male and 41 (67.5%) were female. The meaning of this difference is that, Female use more HIV and AIDs services compared to male group. The findings are in line with Mwale (2016) who conducted a similar study in Zambia and found female use of HIV and AIDs services more than male. The reason behind the findings is due to the fact that fewer men get tested for HIV. [Studies](https://www.ncbi.nlm.nih.gov/pubmed/26035315) show that in East and Southern African countries, men are significantly less likely than women to have been tested for HIV and therefore do not know their HIV status. (Vandormael A et al 2014).

Table 4.1 Sex of Respondents

|  |  |  |
| --- | --- | --- |
| **Sex** | **(n=60)** | **Percent** |
| Male | 19 | 32.5 |
| Female | 41 | 67.5 |
| Total | 60 | 100.0 |

Source: Field Data (2019)

Figure 4.1 Respondents Sex

Source: Field Data (2019).

## 4.2.24 Age of Respondents

Age was considered an important variable in assessing factors affecting retention of people with HIV and AIDS in the care services. The study findings show that 22 (36.3%) respondents were from the age group between 18 and 24 years. 28 (46.3%) respondents were from the age between 25 to 49 years. 10 (17.4%) were from the age group between 48 and above. The statistics signify that all age groups were involved in the use of HIV and AIDs services.

However, a large number of respondents were between age group between 25 to 49 years. The findings also supported by Fritsch (2005) in her study found that, older adults infected with HIV/AIDS had accessing medical and social services, and compared their experiences to those of younger infected adults. The study found that overall, older adults aged 50-plus were able to access the medical and social services they needed to cope with being infected. Most study participants reported positive experiences with medical services. Like younger adults, older adults accessed a variety of medical services and organizations, although to a slightly lesser degree. Older adults also accessed a variety of social and emotional supports and social organizations to a similar or greater degree than younger adults. The older adults’ positive and directive attitude, knowledge of the disease, and available supports, in addition to living in the gay community, explain their ability to access services.

Table 4.2.Age of Respondents

|  |  |  |
| --- | --- | --- |
| Age category  | (n=60) | Percent |
| 18 – 24 | 22 | 36.3 |
| 25 – 49 | 28 | 46.3 |
| 48 and Above | 10 | 17.4 |
| Total | 60 | 100 |

Figure 4.2 Respondents Age

Source: Field Data (2019)

## 4.2.3 Respondents Marital Status

Marital status was considered as an important element to consider during this study. The findings revealed that 41 (68.8%) of the total respondents were married. Among them 19(31.2%) were single. These figures revealed that there was a difference between married and single respondents on the use of HIV and AIDs services. Therefore, the data implies that married people use these services more than unmarried people.

Table 4.3 1Respondents Marital Status

|  |  |  |
| --- | --- | --- |
| Status  | (n=60) | Percent |
| Married | 41 | 68.8 |
| Single | 19 | 31.2 |
| Total | 60 | 100 |

Source: Field data: (2019)

Source: Field Data (2019)

**4.2.4 Respondents Education Level**

Another aspect was education level which was considered as an important attribute to consider when assessing factors affecting the retention of people living with HIV/AIDS to care service in Ilula ward. This was because, education was assumed to have a crucial role in enabling respondents in continuing to use HIV/AIDS care and treatment services. Thomas, M. S., Crosby, S., & Vanderhaar, J. (2019).asserts that educated patients prefer to attend the clinics because they know the consequence of fail to attend. The study found that 49(81.3%) possessed primary education, 5(8.8%) possessed secondary education, 2(2.2%) hold diploma and certificates. Therefore, the statistics implies that majority of the respondents’ possessed primary education. Table No. 4.4 illustrates.

Table 4.4 Respondents` Education Level

|  |  |  |
| --- | --- | --- |
| Education Levels | n=60 | Percent |
| Primary education | 49 | 81.3 |
| Secondary education | 5 | 8.8 |
| Certificate level  | 1 | 1.1 |
| Degree level | 1 | 1.1 |
| Others level | 4 | 7.5 |
| Total | 60 | 100 |

Source: Field data: (2019)

## 4.2.5 Respondents’ Employment Background

In the current study researcher was interested to know the employment status. The findings revealed that 39(65.0%) of the respondents were self-employed, 18(30.0%) unemployed and 3 (5.0%) employed. This implies that majority at Ilula ward were unemployed.

Table 4.5: Respondents` Employment Status

|  |  |  |
| --- | --- | --- |
| Employment status | (n=60) | Percent |
| Employed | 3 | 5.0 |
| Self-employed | 39 | 65.0 |
| Unemployed/not working | 18 | 30.0 |
| Total | 60 | 100 |

Source: Field data: (2019)

Figure 4.4 1Respondents Employment Status

Source: Field Data (2019)

## 4.3 Retention Trend in HIV and AIDS Care Services

Retention in HIV health care services is a critical precursor to ART adherence and viral suppression. Clinical visits for patients on ART are essential to initiate ART, ensure continuous access to medication, monitor medication side effects, diagnose treatment failure, and, when necessary, switch to second- or third-line ART regimens. Retaining patients in care helps them to maintain high medication adherence, thereby achieving viral suppression, improving health outcomes, and reducing the risk of horizontal transmission. People Living with HIV/ AIDS who are not retained in care stop or interrupt ART, increasing their risk of drug resistance and mortality Retaining patients in care over time is problematic. Due to these reasons the researcher interested to know the trend of retention in Kilolo district through Ilula as illustrated below.

Figure 4.5 Are you still receiving HIV and AIDS Care Services

Source: field data (2019)

Results in figure 4.5 above revealed that, majority of respondents (68.8%) were still receiving HIV and AIDS services from health care, only 31.2% were no longer using the services. This implies that there is still a challenge of patient dropout from ART care and treatment centers. Geng et al., (2010) in their study pointed out that there are some patients who decide to drop out of treatment programs in various stages due to the different reasons such as ability of patient to trace different programs and quality of care provided in health facility level. The findings were also supported by health providers who had the following to say:

 *“Currently, in our health care we do not have a big problem of people who drop out from receiving the care services, though few patients drop out due to various reasons such as distance, lack of support and ignorance of few who decided to follow religious faith”.*

Muula (2006) support the findings of the study, he found living far from treatment centers with high transport costs were anticipated to be barrier to care to the people with HIV/AIDS. This is common to most people residing in rural area where the health centers with the service are far from the people’s living places. It is from these circumstances, there is all possibility of losing patients in the course providing care services in most localities.

## 4.4 Economic Factors Affecting Retention to HIV and AIDS Care Services

Retention to HIV care is vital for patients’ survival, to prevent onward transmission and emergence of drug resistance. Travelling to receive care might influence adherence. Data on the functioning of and retention to HIV care in the Central African region are limited; the study assessed several factors of retention including economic factors as follows; In responding to what economic challenges which force them not to attend the care centers, one respondent from Nyalumbu who said;

*I joined this service for almost four years now, for sure there is no charges associated with the services given but rather the cost of transport from where I leave to here is high, and sometime because I need someone to escort me to the centre am forced to pay for that person transport and sometime to give him/her something so that he can escort me in future. Apart from transport cost I buy food because I can’t stay five hours at the centre without eating”*

Another patient from Ng’ang’ange Village said that;

 “*In our centre we are not charged for the services offered, though some health care officers sometime demand bribes for someone to get quick service, apart from that transport and food cost me a lot, and in some circumstance I skip clinics until when I get enough money, …So having facilities nearby will not only ensure convenience but also make a major difference to the financial and health impact HIV can have on my health.*

Additionally, one respondent said that;

*Sometime I wake up in early hours of the morning and I have to pay a nurse so that she can take my file in the front row. If I don’t pay even if I came in the morning, I can sit on the queue forever. One day I accompanied my friend and we arrived in the morning we were told that those who come late have to pay then they put file on top of other files .So there is no respect at all. They have an attitude towards patients as if they deliberately choose to be HIV positive.*

The study findings are also supported by Pinto et al, (2013) who revealed that in Malawi, access to care services incurs several costs depending on geographical locations. It was revealed that, some patients were getting services in the hospital. In this circumstance, the mode of transport to a significant degree determines the state of patients’ retention to care services.

This is also supported by health care officer at Ilula, he assert that;

*“In our health care centre we do not charge any amount for the services offered but most of the patients complained about the transportation cost from their homies as you know our villages are scattered”.*

## 4.5 Social Factors Affecting Retention to HIV and AIDS Care Services

Retention in care for HIV is essential for effective disease management; however, factors that may confer risk or protection for adherence to regular HIV care are less understood. This study tested whether Social factors such as moral support, stigma, religion belief and traditional medicine affect retention to HIV and AIDS care services. In responding to whether there is social and moral support, one respondent from Ukumbi assert that

*“My family support me a lot especially my wife, who always escort me to the clinics and take care me when am sick, but I know one of my friend who never get support from his family and sometime he sleep without eating because no one is around to cook for him… so you can imagine taking all these medicine without eating”*

Another respondent from Nyalumbu said that

“*When I first came to the hospital I had no idea on what kind of disease I had, during this time my family provided all support to me, but after knowing that am suffering from HIV they ran away from me, they were afraid that I may infect them. For sure I felt despair and preferred dying at that time.*

*In that time I put all my trust to health care officers who always encouraged me, I am very close to one of the health care officer and I would like to tell him that everything including my family problems, I always trust him and accept what he says and advised, he is the person who encouraged me to move on.*

The study findings are consistent with the study by Musheke*et al.,* (2012) who found that, HIV/AIDS related stigma is a serious obstacle to a working retention of people in the care systems. Individuals are reported to be rejected, denied, and socially distanced from other community members. It is from this experience the rate of retention always getting down against the expected situation. Additionally, health care workers confirmed that stigma is there at individual and community levels.

*“Stigma still exists among the well-off patients and well known people. Some of them send other people to pick their drugs for them. If health care workers insist on seeing the patient, they would rather stop taking the ARV drugs for fear of being known. This is why they default and we admit them here when they come very sick and weak’- Health care worker*

Moreover, it was confirmed by patients who dropped out from care centers that:

 *“Pastors who preach the gospel of faith healing convince many patients to discontinue ART. They feel healed when they are prayed for. They have faith in these pastors and they would definitely stop taking ARVs. Sometime when they feel sick that’s when they reveal that they had stopped because pastors…Patient from Ng’ang’ange village*

Additionally one patient asserts that;

*“In my case I experienced stigma from my partner, I thought that because we went together for the test, I thought she was going to accept it but in the end she couldn’t accept it. I was scared of people in such a way that most people don’t even know that I have the disease. I kept it to myself and I’m taking of myself. I also make sure that I take my tablets because I don’t want people to know because if I get sick, they will not provide assistant to me”*

This finding of this study is in line with Loggerenberg, Debra and Grants (2017) who said that the fear of appearing ill and therefore being known to be sick was motivating many patients to adhere to treatment.

## 4.6 Health Facilities based Factors affecting Retention to HIV and AIDS Care Services

Based on literature access to health facility significantly contributes to patient’s dropout in accessing the required services particularly long distance to the health facility. In the current study the researcher posed several questions to test whether drug stock, customer care, waiting time, number of service providers and lack of privacy may influence patient’s dropout from services. In responding to the question of whether there is any challenge regarding drugs, customer care, waiting time and privacy, he said that

 *“I always get drugs from the centre, I had never missed the drugs with exceptional for children who are sometimes lack some of the drug items, but what I hate most is poor customer care from health workers like harsh language from them and long queue while waiting the service. Also there is no privacy among workers of the centre which make me to think of shifting to other centre”*

The findings are also supported by one health service provider when responded to the question about the reasons for patients drop out and he had the following to say:

*“Lack of transport fare, lack of enough food and drinks, self-stigma lacks of privacy among clients, supporters and health workers and inadequate counseling during/prior to ART initiation”.*

The findings also supported by Callaghan, Ford and Schneider (2010) who found in their study that, shortage of personnel may result in long waiting for the patients at the service providing places which ultimately results to patients’ frustration and being discouraged of seeking services resulting to poor retention in the care services. It is further argued that, most health centers suffer from the shortage of mentors in the course of service provision. The lack of mentors contributes to loss to follow up in the provision of services because the patients require the mentoring services in order to guide and instruct them in the course of services provision.

**4.7 Patients’ Related Factors that affect Retention to HIV and AIDS Care Services**

The current study also examined patients’ factors that affect retention to HIV and AIDs care services by posing several questions regarding perceptions, alcoholism and drug consumption

*“I am very positive on the ART drugs because many people are healthier because of them, so I will take throughout my life. Previous I used to skip taking them this was due to alcohol consumption which make me forgot the clinic date or even to take the medicine on time, but now I have changed my behavior of drinking too much”……patient from Lugalo village*

Another respondent from Nyalumbu assert that

*“I take alcohol to make my brain relax, because alcohol help me to relieve stress and act as an appetite stimulant. You know to leave with HIV is not a simple issue because I experience amount of emotional distress and alcohol provide me with relief. I agreed that sometime I forget to take medicine because of being too drunk. I wish to stop taking alcohol because one of the health officer told me that regular consumption of alcohol weaken my immune system and damage liver, as well as lead to risky behaviors’ that increase the chances of passing it on to others……..patient from Nyalumbu*

The findings of the current study also confirmed by the interview results from a patient who dropped from care centre and had the following to say:

 *“It has been now close to one year and a half since I stopped my ARV treatment. I just stopped taking my ARV drugs because of beer drinking’. When I got drunk, I used to forget taking my drugs and eventually I stopped my drugs’ – 42 years old man”.*

Another respondent from Uhambingeto said;

*“ ..I have noticed how beautiful I have become after taking these tablets…. I don’t think I ever stop taking them. I was sick, I was very sick by then, I’m not exaggerating…. I was raised from dead”*

*You can’t stop taking these tablets because …like me.. They woke me up from the grave. They are now my life. I will only stop taking them when I’m dead, when I’m no more, because they are my life”…. Patient from Uhangimbeto*

Respondent in Ukumbi add that:

*“I had no fear about ARVs side effects because I used to taking tablets. I have taken too many tablets in my life. And the tablets I am taking now are far less because I only take four tablets.*

The findings are contrary to Musheke*et al.* (2012) who said patients consider the side effects of the drugs lead to unfavorable condition to their health and disturb their normal activities and that is why they discontinue with treatment but the study findings are also consistent with Musheke on the aspect of alcoholism and drop out from health care centers.

# CHAPTER FIVE

# 5.0 CONCLUSION, POLICY IMPLICATION AND RECOMMENDATIONS

## 5.1 Overview

This chapter presents the summary, conclusion and policy implication of the study on the retention of people living with HIV and AIDS in Ilula. The chapter is divided into three sections. The first section summarizes the results and conclusions of the entire study; the second section presents the implications of the study, where policy implications and the areas for further study are presented; whereas the third section provides the limitation of the study.

## 5.2 Summary and Conclusions

The purpose of the study was to examining the factors affecting the retention of people living with HIV/AIDS to care services in Ilula ward. Specifically, the study aimed to examine the economic factors affecting retention of people with HIV and AIDS in the care services examine Social factors affecting retention of people with HIV and AIDS in the care services and lastly to examine how health facility based factors and patient related factors affecting retention in this care service.

The study was qualitative using structured interviews to collect the data probability and sampling was employed to select a representative sample from each stratum, from which a sample size of 60 respondents informed the study. Descriptive statistical methods where adopted to analyze data obtained from respondents, while SPSS version 20 and excel Microsoft application were used to process the data. Thematic content analysis employed to analyze the qualitative data, where presentation wasbase on themes. The study results indicated that patient, social; health systems and economic concerns affected patient retention in care particularly poor customer care, travel distance to ART center, cost of transportation and high patient load with long waiting times at the clinic represented the greatest barrier to accessing treatment. In additional, HIV related- stigma and non-disclosure of HIV status to sexual partners and families are significant barriers. However, if the needs of patients are to be met, systems in health facilities need to be strengthened to reduce loss to follow up, increase adherence and promote long term retention.

## 5.3 Results Implications

The study findings found that majority of respondents were able to identify the number of factors that led them to stop attending HIV/AIDS care and treatment as a means to improve their health. Most of the measures that were suggested includes, closer patient follow up, privacy for service providers, improvements of infrastructures for services provision, recruitment of health service providers and awareness rising to the community on their role in supporting HIV/AIDS patients. All the suggestions mentioned were identified to be effective. In this cause the for the improvements of the services to PLHIV especially in retention to ART care and services there must be several implications.

## 5.3.1 Policy Implication

The study results indicate that some of the patients admitted drug stock out for children in the health facility contribute to drop out from care services. It advocates that the government can ensure drugs are distributed and delivered to all care centers. Also, since there was a complain on customer care because of shortage of skilled persons which will enable the care centers to serve time within a reasonable timeframe hence low drop out from centers. Limited access to care center because of long distance from their home was among the reasons for drop out from health care services, also most of the respondents said they need fare for transport from their homes to clinics, in this situation the government can set enough budget so that many centers’ can be established. It would also be useful to introduce community drug distribution points for delivering ARV refills to reduce on distance that patients have to travel to the health centers as well as reduce congestion at health facilities. Making ART more accessible could be critical in enhancing retention of patients in ART programs.

Health workers should also be equipped with the required knowledge and skills including quality assurance and improvement of skills to manage patients on ART. Task shifting involving the people living with HIV should be a priority in ensuring patient retention in care. These cadres need to be motivated for them to work more efficiently and effectively in the delivery of ART services. This study therefore, recommends guidelines on task shifting to include clear guidance on remuneration for lay workers and adherence support workers for the delivery of HIV care services. As it stands now, the amount given to community health workers across organizations is different. There is need to standardize the reimbursement system. The policy makers should also consider appropriate employment opportunities for community cadres such adherence support workers and other lay workers.

## 5.3.2 Areas for Further Studies

Based on findings in this study and methods applied, I recommend the future researchers to undertake critical correlation studies to examine the role played by other factors like government policy for retention of patients under ART. Therefore, for other researchers it is recommended to lengthen the study to other factors and different areas across the country.

## 5.4 Recommendations

Based on the findings several recommendations were posed by patients, health workers and community at large.

1. Community recommends close follow up should be done by both family members and health workers to make sure they attend clinics. They suggested reminding them through phone call and messages and counseling.
2. Establishment of Saturday clinics which will make people who find normal week days to be busy for them. Also teen’s clubs to be established.
3. Due to poor services from health workers it is recommended that the number of health workers should be increased so as to reduce workload to the existing workers which in turn will enable them to work within minimum time.
4. Health workers recommend establishment of community based health service (CBHS) programs in each village to make service more accessible.

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# APPENDICES

APPENDIX I: RESEARCH PLAN AND BUDGET

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **NA** | **ACTIVITY**  | **PARTICULARS** | **ITEMIZED** | **COST** |
| 1 | Material collection for research | Books, Journals, periodicals, Texts and consultations | lump sum | 350,000.00 |
| 2 | Consultations | Research Assistants (Key informants)  | meals &transport  | 40,000 |
| 3 | Data collection devices | Conducting interviews andand FGDs;  | Food and Transportation @10,000 x 2 x 20 days | 400,000.00 |
| 4 | Report construction | Production &Dissemination | LAMPSUM | 1,000,000 |
| 5 | Transportation | Trips | Researcher @ Local trip 20,000/= x 20days | 400,000 |
| 6 | Food and Refreshments | lunch | Lump sum | 300,000 |
| 7 | Stationary | Printing and photocopying | Printing, photocopying, Pens, papers, pins | 150,000 |
| **TOTAL** | **2,640,000** |

APPENDIX II: ACTIVITIES PLAN

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **ACTION** | **JUN2019** | **AUG 2019** | **SEPT 2019** | **OCT 2019** | **NOV 2019** | **NOV 2019** | **DEC 2019** | **JAN 2020** | **FEB 2020** | **MAR 2020** |
| Proposal Preparation & Draft Submission |  |  |  |  |  |  |  |  |  |  |
| Proposal Correction Submission & Departmental Presentation |  |  |  |  |  |  |  |  |  |  |
| Data Search, Collection, Organization and Analysis |  |  |  |  |  |  |  |  |  |  |
| Report writing and draft submission to supervisor |  |  |  |  |  |  |  |  |  |  |
| Report Correction and final Submission |  |  |  |  |  |  |  |  |  |  |

APPENDIX III : INTERVIEW GUIDE FOR HEALTH SERVICE PROVIDERS AND COORDINATORS.

I am studying Masters of Social Work (MSW) at the Open University of Tanzania. I have designed the following questionnaire for the study of the Retention of People Living with HIV AND AIDS in care services in Iringa Tanzania: Evidence from care and treatment centre at Ilula ward in Kilolo District”. I would highly appreciate if you fill this three-page questionnaire. It will take approximately 10-20 minutes. I expect your positive cooperation in this respect.

1. How many clients are enrolled in this centre since HIV and AIDS cares services were introduced in this clinic?
2. Is there any follow up since the services started?
3. Do patients pay for any of the HIV related services at this clinic?
4. Are you experiencing stock out of HIV and AIDS drugs in this clinic?
5. How many health service providers are assigned to deal with HIV patient in this clinic? How Many days are assigned for HIV patient clinic per week?
6. Can you say something about retention rate for ART patients at this clinic?
7. What are the reasons for people living with HIV and AIDS enrolled in the care to drop out?
8. Do you think there is any belief that influence HIV and AIDS patient to discontinue from services?
9. What other causes of HIV and AIDs patients to drop out from services?
10. From your opinion what should be done to ensure that HIV patient who start on treatment at this clinic do not run away?

APPENDIX IV:

INTERVIEW GUIDE FOR PATIENT RETAIN IN CARE AND DEFAULTERS

I am studying Masters of Social Work (MSW) at Open University of Tanzania. I have designed the following questionnaire for the study of the Retention of People Living with HIV AND AIDS in care services in Iringa Tanzania: Evidence from care and treatment centre at Ilula ward in Kilolo District”. I would highly appreciate if you fill this three-page questionnaire. It will take approximately 10-20 minutes. I expect your positive cooperation in this respect.

* + 1. Are you still receiving HIV and AIDS care services?
		2. How could you rate the HIV and AIDS care services provided in this center
		3. Is there any payment associated with the HIV and AIDS services which prohibit youfrom continue with service? What are they?
		4. Do you incur any cost while accessing services from HIV and AIDS clinic results to patients drop out from care services?
		5. Do you get social and moral support from family and community?
		6. Do you face any stigma and discrimination from family and community? Mention those stigmatization you experience
		7. Does religious belief and traditional medicine influence people living with HIV/AIDS to stop attending clinic for care services
		8. Have you ever experience drug is out of stock in your centre?
		9. Can you share with us the kind of customer care from health worker?
		10. What other challenges do you experience when accessing services in this clinic?
		11. From your opinion what should be done to ensure that HIV patient who start on treatment at this clinic to retain?