DETERMINE FACTORS TO RETENTION IN CARE FOR HIV POSITIVE CLIENTS ON ART IN SIOMA DISTRICT- WESTERN PROVINCE, ZAMBIA.

By

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DECLARATION

I **Jones Lyuba** do hereby declare that this proposal titled, "Determine factors to retention in care for HIV positive Clients on ART in Sioma District- Western Province." is my own original work. It was guided by my co supervisor and marked by my supervisor in accordance with the guidelines for Master of Public Health at the University of Zambia. It has not been submitted elsewhere for a Master's degree at this or another University.

Signature: ……. **Date:** …….

APPROVAL

This dissertation of Jones Lyuba has been approved as partial fulfillment of the requirements for the award of the degree of Master of Public Health by the University of Zambia.

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ABSTRACT

Introduction: Keeping clients in care is essential to achieving strong patient outcomes and prevent treatment failure or resistance. Globally, HIV/AIDS remains one of a major public health problems with an estimated 38.4 million people are living with HIV while 1.5 million people become newly infected with HIV annually. HIV/AIDS has continued to be a major public health challenge even for Zambia, with the highest HIV prevalence rate of 13.1% in sub-Saharan Africa. Although the government of Zambia has increased the availability of ARVs in all the health facilities in the country and ensured that all HIV positive clients are put and retained in ART by means of "Test and Treat" program, not all patients who are initiated on antiretroviral treatment remain in care; with some patients being lost at different points in the continuum of care. Hence, this study is aimed at determining several factors to retention in care for HIV positive clients and their outcome at 4 health facilities in Sioma District in Zambia.

Methodology: This is a retrospective cohort study, from period February, 2020 to February 2023, used a systematic quantitative method of collecting information or data by reviewing pre-existing data of a sample of an individuals as well as by administering research questionnaires to HIV defaulters. To determine the geographical, sociocultural, Health systems and medical condition factors that underlie retention and its outcome in selected primary health facilities in the district. Sample size was calculated using Kaplan Meier formula with confidence interval of 95%.

360 defaulters were studied on and data was analyzed using Kaplan Meier curves and Log rank tests in STATA to determine the survival outcome of all defaulters over time.

Findings: The overall retention rate of the ART sites was found to be 89% for client initiated 3 years ago. With reduced mortality survival rate of 86% from 100% of the non-defaulters, while the morbidity survival rate was at 39% compared to over 95% for non-defaulter clients. The median duration of follow-up was 18 months (0-41). At 12 months, the Date of Death-free survival was 85.7% (95% CI: 53.9-96.2) and at 24 months, the Date of Death-free survival was 38.6% (95% CI: 13.4-63.6).

The survival rate for HIV defaulters reduced over time, as the defaulter rate increased over time. Most of the mortalities 67% (n=6) occurred within 12 months after stopping taking ARVs. This applies to the increase in the occurrence of Opportunistic Infections (OIs) over time after clients stopped taking ARVs. The majority developed OIs 93% (n=313) within 12 months, 100% of mortalities were associated with OIs.
Geographical and sociocultural factors were the major contributors to poor retention in the district accounting for over 62%. 214 of all respondents stopped taking ARVs because of long distance (> 12 KMs) for drug pickups, while 6% (n=25) was due to floods and cut off reasons.

***Keywords**: HIV Retention Outcome*

DEDICATION

This thesis is dedicated to my late dad, who though absent has continued to inspire me and influence my character and hardworking spirit. He continues to hold a special place in my heart. May his soul continue to rest in eternal peace. I also want to dedicate this thesis to my son, mum, siblings and wife who have been very supportive throughout my career. I can only pray that my God bless them abundantly

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	: Acquired Immune Deficiency Syndrome
ART	: Antiretroviral Therapy
ARV	: Antiretroviral
CDC	: Centers for Disease Control and Preventions
CBVs	: Community Based Volunteers
CSO	: Central Statistics Office
DHIS2	: District Health Information System
DHS	: Demographic and health survey
DHIMS	: District Health Information Management System
DHMT	: District Health Management Team
EAC	: Enhanced Adherence Counselling
HIV	: Human Immunodeficiency Virus
LTFU	: Lost to follow up
MDG	: Millennium development goal
MOH	: Ministry of Health
NAC	: National AIDS Council
NBVs	: Neighborhood Based Volunteers
PLHA	: People or Person Living with HIV and AIDS
STI	: Sexually transmitted infections
UNAIDS	: Joint United Nations Programme on HIV/AIDS
USAID	: United States Agency for International Development
VCT	: Voluntary counselling and testing
WHO	: World Health Organization
ZDHS	: Zambia Demographic and Health Survey
ZCGs	: Zambia Consolidated Guidelines for HIV treatment and Prevention

DEFINITION OF TERMS

Retention: 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. In this current study retention was determined by a patient attending the last scheduled follow up appointment within 28 days of missing appointment. (MOH, 2022, p. 81)

Attrition: This is the discontinuation of ART including death, loss to follow-up, and stopping ARV medications while remaining in care. (MOH, 2022, p. 81)

Loss-to-follow-up: The phrase, lost-to-follow-up, is frequently used in health care to describe patients who you can no longer be located despite best efforts from health care providers. This implies that it is either the patient's fault, or due to circumstances beyond one's control. In the current study, it refers to patients receiving ART who were more than 3 months late for a scheduled clinic or pharmacy visit, and who were neither transfer-outs nor relocations. (MOH, 2022, p. 82)

Adherence: Adherence is defined as the correct and timely dosing of prescribed medication by the health care provider. In this current study, adherence focused on both taking medication appropriately as prescribed and attending clinical follow up appointments as scheduled. (MOH, 2022, p. 82)

Antiretroviral drugs: These are the drugs that specifically work to suppress HIV replication.

CHAPTER ONE

INTRODUCTION

1.1. Background of the study

Keeping clients in care is essential to achieving strong patient outcomes and prevent treatment failure or resistance (MOH, 2022, p. 81) . Globally, HIV/AIDS remains one of a major public health problems. An estimated 38.4 million people were living with HIV by the end of 2021 (UNAIDS, Global HIV & AIDS statistics — Fact sheet, 2022, p. 1)while 1.5 million people became newly infected with HIV in the same year. (WHO 2021) with 650 000 HIV related deaths and 87% retention rate (UNAIDS, Global HIV & AIDS statistics — Fact sheet, 2022). Failure to retain HIV positive clients to care is highly unacceptable as it leads to High Viral Load, increases incidence of Opportunistic Infections (OIs) and drug resistance in people living with HIV (MOH, 2022).

The third UNAIDS PEPFER HIV target by 2030 is to ensure that 95% of the clients on ART are retained in care and virally suppressed even amidst Covid-19 pandemic. (MOH, 2022, p. 116).

Zambia has a population of 19.17 million people (ZDHS, 2021) and it is one of the Sub Saharan African countries worst hit by HIV and AIDS epidemic (UNAIDS, Global HIV & AIDS statistics — Fact sheet, 2022). In Zambia, the HIV prevalence is estimated to be 11.3%, “Annual incidence of HIV among adults aged 15+ years in Zambia was 0.31%, which corresponds to approximately 28,000 new cases of HIV per year among adults. HIV incidence was 0.56% among women and 0.06% among men. Prevalence of HIV among adults aged 15+ years in Zambia was 11.0%. HIV prevalence was 13.9% among women and 8.0% among men (ZAMPHIA, 2021, p. December Report) with Prevalence of VLS among adults aged 15+ years living with HIV in Zambia was 86.2%. (pp. ZCG, 2022, 81) (WHO, 2021, p. 152)Note that these estimates of VLS prevalence are among all adults living with HIV, regardless of their knowledge of HIV status or use of antiretroviral therapy (ZAMPHIA, 2021, p. 1)). At the end of 2021, 1.3 million people were living with HIV in Zambia, of which about 1.2 million were maintained (MOH, 2022, p. xi). HIV is the leading cause of death for all ages in Zambia. During the 2021 period, 19, 000 people died due to HIV/AIDS related conditions (UNAIDS, 2021)). Sadly enough, out of the 1.2 million people living with HIV in Zambia, only 89% were retained to care (UNAIDS, 2019).

In Sioma District, retention rate is at 87%, meaning that Sioma District is also contributing to poor retention of HIV positive clients enrolled in care after 6, 12 and 24 months respectively. (DHIS2, 2023)

In an effort to improve retention rate and achieve the Sustainable Development Goal target 6 and epidemic control, the Zambia Ministry of Health has strategized to increase access to quality Health Care system (MOH, 2022) and skilled ART providers, CBVs and medical and clinical mentors with region CLOs in the District. Two Health Facilities has been built recently are to be made ART static sites. (DHIS2, 2022).

1.2. Statement of the problem

The introduction of quality ART and its scale up has led to the improved quality of life of people living with HIV and AIDS in Zambia. However, not all patients who are initiated on ART do remain in care. Evidence shows that more than 11% of patients discontinue treatment through death or lost to follow up (UNAIDS 2020). DHIMS (2019 – 2020) indicate that only 89% of ART patients are retained in care at 24 months after initiating treatment (ZAMPHIA, 2021) while a research which was conducted in Lusaka in 2019 shows that; 'Among 86,688 patients who initiated ART during the study period in Lusaka Province (where we sought to estimate the prevalence of viremia), 68,934 were retained in care and 17,754 were lost to follow-up.' (Sikazwe I E.-W. I., 2019). Retention in care is one of the critical issues that needs to be addressed in Zambia if the goal of ending the AIDS pandemic by 2030 is to be realized. Although research has been conducted on patients in ART programs in Zambia, most studies have focused on facility based adherence monitoring and factors associated with poor adherence to ART. (T. Heestermans, 2016) Retention of patients in care, though recognized as a prerequisite for achieving any level of adherence, has received less attention. (Nardell MF, 2022) Retention to care for patients on ART program is of public health importance. Therefore, a better understanding of the factors affecting retention in care of patients on ART program in Sioma is needed.

By the end of 2022, there was poor retention rate (which was at 87% for the clients enrolled in care 12 and 24 months ago respectively) (DHIS2, 2023) in Sioma district which is linked to several factors, and if these factors were to be studied analysed and mitigated on, we will be able to meet and sustain HIV epidemic control with above 95% retention rate in the district.

1.3. Objectives

This proposal's goal is to determine factors associated to retention in HIV positive clients on ART and its impact to ART clients in Sioma District- Western Province.

Specific objectives:

1. To identify medical related/comorbidities factors contributing to HIV retention in the district
2. To identify health system factors contributing to retention in the district. To identify Clients' health seeking behavior affecting retention in the district.
3. To determine geographical and socio-cultural factors that contributes to retention in the district.

1.4. Research Questions

a. Has Psychosis, TB, Covid-19 and other comorbidities contributed to low ART retention in Sioma?
b. Does the health system in Sioma favors retention in care for HIV positive clients?
c. Does long distance and floods contributes to poor ART retention in Sioma?

1.5. Conceptual Framework

A conceptual framework is also known as the conceptual model in a practical way, it is defined as a visual representation in research that helps to illustrate the expected relationship between the cause (Factors), effect and outcome. It is further called the research model. (Mulder, 2023).

Medical conditions affecting HIV positive clients like TB, Covid-19, Meningitis, psychosis, cancers and physical disabilities, sociocultural factors like the usage of herbal medicine instead of ART, lack of transport money for pharmacy pick-ups as well as poor health systems to favour HIV positive client's safety, privacy and confidentiality are correlational to poor retention in Zambia.

Hence, the concept is intended to see how this relation are correlational in order to find new workable interventions towards these factors to improve Retention in ART which will eventually improve health among HIV positive clients in Sioma District . If these factors are not studied and

addressed, the consequential outcome will be increased HIV related morbidities and mortalities in the District.

Below is the pictorial conceptual framework.

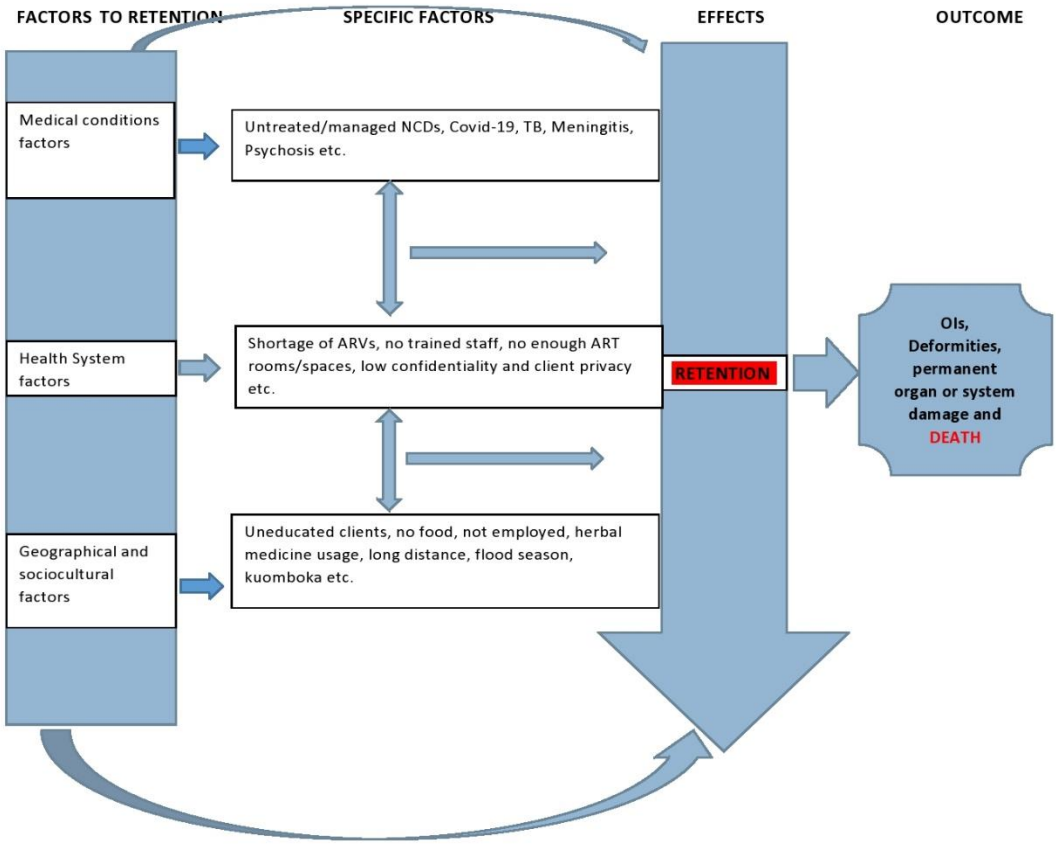

Figure 1. ***Conceptual framework for HIV retention factors***

Health systems factors

- Knowledgibility and trained staff: only well knowledgeable and trained staff are able to provide quality ART services
- Staff Attitudes: staff's attitudes toward PLWHIV are not good, hence clients feels been disrespected by health workers, leading to discrimination and stigmatization.

- Environmental Structural: some ART rooms are not in good shape, some are too small to accommodate clients' privacy. Hence, clients are forced to resort to shunning away from receiving ART services due to stigma.

Geographical and Socio-cultural factors

- Cultural Herbal medicine use- most clients tends to start using herbal medicine instead of ART, once their ATD (African Traditional Doctor/Healer) tells them to do so.
- Social Factors

a. Long Distance and bad road network system: Most clients are coming from remote areas where the road network system is very poor, and it is very difficult for them to find the mean of transport to come to the health facility especially for Enhanced Adherence Counselling (EAC). The distance from the facility to their homes and the next referral level is long and the road network is extremely bad, sandy and more often flooded in rain seasons, the road tends to be impassable by cars or ambulances.

b. Poor income: their source of income are seasonal, only have their money after selling their crops and fish, hence they are poor because even the crops they harvest, some of them are not enough to feed them the whole year. Therefore, it's very difficult for them to find their own transport on time to come to the clinic for Drug Pick-ups.

c. Illiteracy: most clients in rural setups don't know how to either ready, write or count, they don't even know how old they are or when they were born. This makes it very difficult for them to remember or know the dates they are supposed to be coming for reviews or drug pickups.

- Geographical factors

a. The whole district is in a bad sandy road with about 60% of health facilities in plan areas which are usually in floody during rainy season up to June, poor to no network system in most facilities making it very hard for the CBVs to track patients, even for the patients to come for drug pick-ups.

Medical factors

The district has HIV positive clients who are suffering from other Medical, physical and mental conditions making it difficult to keep pharmacy appointments

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

Literature review is a comprehensive summary of previous research on the topic, in this literature review, numbers of research scholarly articles will be summarised, reviewed, analysed, interpreted, and critically evaluated.

In this HIV retention studies conceptual framework, I have explored the factors affecting patient retention in HIV care globally, in sub-Saharan Africa and in Zambia.

Taking antiretroviral treatment (ART) is a lifelong commitment that requires patients to adhere to their prescribed treatment to prevent disease progression and promote optimal health. ART allows people living with HIV to live longer, have a better quality of life and experience fewer illnesses related to HIV. Despite the known facts of the benefits of ART (PAHO, 2023).

2.2. Factors that affect Patient Retention to HIV Treatment

Attrition from ART care is not exclusively a clients' choice, because it is pretentious by other factors which interact to influence patient seeking behavior (Musheke, 2023). The factors affecting the retention of patients in ART programs can be categorized as: patient, cultural, social, health systems, geographical and economic related factors. Reported a poor sense of self-efficacy among patients receiving ART treatment to have led to discontinuation of treatment (Musheke, 2023)argue that a sense of wellbeing in patients receiving antiretroviral treatment decreases motivation to continue on treatment.

2.2. 1. Health Systems Factors

The health systems plays a major role in ensuring retention to care of patients living with HIV on ART, if not, attrition will continue to rise. *Attrition rates continue to rise among people initiated on ART. This requires health care providers and public health agencies to pay attention to this issue in order to improve retention rates thereby improve patient outcomes for the larger population.* (Mwale, 2017).

Programmatically, *Loss to follow up refers to patients receiving ART who were more than 1 month late for a scheduled clinic or pharmacy visit and who were neither transfers-out nor relocations* (MOH-Zambia, 2020)*.* It represents patients who have died, self-transferred to another facility and those who are alive but voluntarily withdraw from care. *In this setting, attrition almost equates to*

loss to follow-up because mechanisms to establish death, transfer or defaulters amongst the patients are not in place (Mwale, 2017).

This is true especially in ART programs that lack capacity to trace and monitor patients outside the confinements of the clinic, but attempts has been made. *Attempts at establishing the actual causes of loss to follow-up by Zambian and Ethiopian investigators reported that 6% and 8% of patients were actually dead 2 years after initiating treatment* (Musheke, 2023).

It has been proven that a good number of those lost to follow ups clients were due to none satisfaction health care services they received from the facility. *Variations in the magnitude of loss to follow up may result from various capacities for patient tracing across different programs. Additionally, variations in the quality of care offered at health facility level as well as other factors may have an impact on the retention rates* (Mwale, 2017).

Some people stopped taking ART because of drug related problem, "Some PLHIV have concerns about the dangers of treatment to their lives and long-term health. One respondent narrated: "*Those drugs almost killed me. I almost went mad. Today, if I was still taking those drugs, I would either be mad or I would have died by now*" (Musheke, 2023).

Sometimes people opted to stop ART because of long time waiting on the chair to be seen by the health care worker. *Competing priorities and dissatisfaction with ART care. When livelihood problems and low perceived quality of care coalesced, incentives to stay on treatment diminished. For some PLHIV, long waiting time and frequent trips to the clinic presented enormous opportunity costs which they were not willing to forego.* (Musheke, 2023).

Shortage of health personnel at the facility (Mukumbang, 2023)is among the drivers of poor retention of patients in care. *Increased number of patients on ART decreases the quality care delivery, making it very difficult to maintain the population level adherence* (Mukumbang, 2017, p. 2)Task-shifting should be considered for careful implementation if we are to offer high-quality, cost-effective care and retain more patients in care. (Mills, 2014) *Healthcare providers and patients identified staff shortage as a factor influencing retention in care of patients on ART. This is because staff shortages lead to long queues at the clinic waiting area and, consequently, long waiting times. Because of this, patients get frustrated and tired of waiting to be seen.* (Mwale, 2017)

These can lead to frustrations with most patients not returning to the clinic especially patients in employment. (Mills, 2014)Some people cries of lack of privacy in most clinics leading to ART discontinuity. *Healthcare providers reported limited space within the ART clinic as being a challenge towards the implementation of ART. This can have an impact on patient adherence and long-term retention. Participants reported using any free room or an empty office, which do not provide a waiting area for patients. In this case, confidentiality (privacy) during ART clinic is compromised because of overcrowding of patients*. . (Mwale, 2017) *According to C. Mwamba, health system hardware's factors influencing patients' disengagement includes inadequate in to protect privacy….chronic understaffing…* (Mwamba, 2021). This was also supported by David and Sikazwe. (David, 2020)

In other facilities, the attrition is because facility staffs are failing or forgetting to update these client's details in their electronic or paper based registers and files. (Smartcare, 2023).

2.2.2 Medical conditions factors

Barriers to retention in care and adherence to medication could lead to increased morbidity and mortality in patient through suboptimal viral suppression, increased risk of resistance and transmission, *and the major contributors was obesity(weight gaing) alcohol abuse, psychosis with stigma* (Mwale, 2017)**.** But there are more condition that affect ART retention in Zambia *and these are TB, Meningitis, Pneumonia, Covid-19 and many more…* (MOH, 2022, pp. 90-139).

Sadly enough even adolescent and young people are facing challenges to continue on ART due to mental health related issues. *…"this is a very tough situation, it is giving me depression."* (UNICEF, 2021)

The other group of individuals dropped out of care because they were in an advanced clinical stage of HIV which is stage 3 and 4, while others had poor functional status. (Moges, 2020)

2.2.3 Geographical and Socio-cultural Factors

a. Cultural factors: western province of Zambia has a cultural ceremony called kuomboka ceremony, during this ceremony sexual activities tends to be at pick. In upper land of the barotse land, there are a lot of ATHs to give herbal medicine to these clients on ART. *PLHIV accessed herbal remedies either from traditional healers or from herbal medicine traders. Some of these remedies were being used either as purported cures or as "immune boosters". These remedies included crocodile fats, moringa oleifera and aloe vera gel (also locally available in plant form*

called tembusha). While some PLHIV initially used herbal medicines concurrently with ART, overtime, they reported exclusively opting for herbal remedies. For some, opting for alternative treatment was triggered by ART-induced side effects, dissatisfaction with ART care and inability to stick to the stringent ART regimen. For other PLHIV, the quest to get cured attracted them to use herbal remedies. (Musheke, 2023). Then those who believe in God as a supernatural healer of all diseases tend to stop ART once they are convinced about this by their pastors or priests. ...*sometimes forced them to opt for faith healing and traditional medicine*. (Musheke, 2023) Use of herbal remedies to treat HIV related illnesses was reported by both patients and healthcare providers as a cause for discontinuation from the ART programme. Some patients were being told that herbal remedies could cure HIV and AIDS. This influences the health seeking behaviours of patients, leading to discontinuation of ART. *The use of herbal medicines was also reported to have been easily accessed by some patients especially those from rural settings and that people have confidence in traditional healers.* (Mwale, 2017)

b. Social factors that influence retention in care include poor social support, relationships with marital partners, family members, or peers including stigma. (Mukumbang, 2023) *Patient attrition from ART care is influenced by an interplay of personal, social, health system and structural-level factors.* (Edwin, 2023)*While improved corporeal health, side effects and need for normalcy diminished motivation to continue with treatment, individuals also weighed the social and economic costs of continued uptake of treatment. Long waiting times for medical care and placing "defaulters" on intensive adherence counselling in the context of insecure labour conditions and livelihood constraints not only imposed opportunity costs which patients were not willing to forego, but also forced individuals to balance physical health with social integrity, which sometimes forced them to opt for faith healing and traditional medicine*. (Musheke, 2023)**[31].** People living with HIV avoid disclosing their HIV status to their spouses, social network or other family members for fear of marriage breakdown, rejection, discrimination and loss of employment. *When social support is threatened by involuntary disclosure of HIV status, individuals abandon treatment as a protective mechanism* (Musheke, 2023). Some it is because of the nature of their job, farmers tend to stop taking ART during their farming season. *Patients who travel for work purposes from their hometown tend to miss clinic appointments and default ART and this contributes to non-adherence and poor retention. Two participants mentioned truck drivers who had defaulted treatment for months and then reappeared again for treatment*. (Mwale, 2017) HIV

and AIDS related stigma is a serious obstacle to long term retention. It can be at individual, household and community levels and it is characterized by rejection, denial and social distance (Musheke, 2023). Many people still associate HIV/AIDS with moral decadence and promiscuity, ultimately passing moral judgment on those infected. Some people tends to be drinking alcohol and forget about taking ART. *Excessive beer drinking was reported to affect patient retention in care and subsequently medication adherence. Some patients reported displaying heavy drinking behaviours after registering great improvement in their health. This eventually leads to discontinuation of ART*. (Mwale, 2017). If universal access to treatment is to be achieved, effective strategies addressing stigma and discrimination must be developed. Stronger community involvement in the process of stigma analysis and development of responses is recommended. *Insecure labour conditions: For some PLHIV, the fear of losing their jobs on account of their HIV status, anticipating stigma, hindered them from accessing treatment. Most people, even when employed, did not have proper contracts which would protect them in case of illness as foreseen by the law. People with job insecurity who also reported earning meagre income did not want to lose their livelihoods on account of disclosure of their HIV status. The lack of both formal and strong informal social safety nets reinforced the need to preserve sources of socio-economic support.* (Musheke, 2023). Food insecurity also contributed greatly to poor retention, as clients opted to go look for food instead of visiting the facility for drug pick-ups. (S. Young, 2014)

c. Geographical factors: very long distances from clients home, floody bad road and poor to no network coverage in most facilities in western province of Zambia makes it very difficult for both CBVs and clients to come for drug pick-ups, hence poor retention in the district. *Although ART sites do not charge for HIV related services, travel distance and additional costs incurred traveling to ART centres may contribute to nonretention in the care of patients on ART programme more so for patients who cannot afford it. While some participants reported travel distance to ART centres as a barrier to accessing treatment, others also mentioned lack of money to pay for transport*. (Mwale, 2017).

Retention in care after initiation of patients on ART has been a focus of every ART programs and is seen as a key indicator of program performance (WHO, Retention in HIV programmes, defining the challenges and identifying solutions., 2011). However, studies on retention across Sub-Saharan Africa have come up with varying 8 results on retention rates and they have shown that not all

patients remain on treatment; some patients decide to drop out of treatment programs due long distances (Geng, 2022).

Taking ART in circumstances of high food insecurity and lack of finances may also increase the chances for absence from the clinical appointments and may compromise retention in care due long distances. (Tuller, 2023) …*long distance to health facilities which costs clients time and money*… (Mwamba, 2021)

Community tracking and tracing programs in which patients with missed visits are traced through phones or home visits using adherence support workers within 24 hours of missing appointments has also helped to retain patients in ART programs. *A missed appointment is a first step of a patient fall-out of care. Therefore, all ART centres must have a dedicated individual to manage the appointment system. Ideally, a list of scheduled appointments should be prepared a few days before the scheduled appointments and patients must be reminded to come for their appointments. Those who miss appointments should be tracked should as soon as possible* (MOH-Zambia, 2020). The use of electronic reminders such as text messages and fortnight phone calls from health care providers in Zambia (MOH-Zambia, 2020) helped to avoid missed appointments and reduced lost to follow-up.

In summary, retention in care remains a public health concern in Sioma ART program cascade because only about 87% of patients are retained in care at the end of two years on ART. Literature reviews strategies that would improve patient retention with the help of all stakeholder involvement in the care of patients. DSD models implementation, extended clinic hours, community program models using expert clients to distribute ARVs in the community as well as community tracing programs though we are still facing challenges to bring to zero attrition rate in ART.

CHAPTER THREE

METHODOLOGY

3.1 Study setting

The study was conducted in the Sioma district of Western province in Zambia targeting 4 High volume Health facilities. Sioma district is one of the 13 districts in Western province of Zambia supported by CDC-Zambia. *It is located on the bank of the mighty Zambezi River with the capital which lies at Sioma*… (Wikipedia, 2023).

District oversees one mini hospital namely; Nangweshi Mini Hospital which services about 17 Rural health facilities and 1 one Urban, with the overall district population of about 50, 773 for 2021. (Sioma/DHO, 2022).

The referral Hospital is accessed by a gravel and sandy road which has a number of floods the road, making it quiet difficulty to cross during rainy and floody seasons.

Generally, the district has high (70%) poverty levels due to high unemployment rates because the district only have one timber company offering very limited employment to the local people. Economic activities are mainly informal, though a few people are formally employed. Most people employed perform low-income jobs like taxi driving, house servants and general workers, shop keepers and so on. Other occupations include employment in Government, parastatals and the private sector.

This study was conducted at four (4) of the government and the United States of America Cooperative Agreement (CoAg) supported ART facilities in the district. Namely: Sioma UHC, Sitoti RHC, Nangweshi RHC and Kaunga Mashi RHC. With low retention rate which stands at 92%, 81%, 90% and 76% respectively. All these clinics were randomly selected.

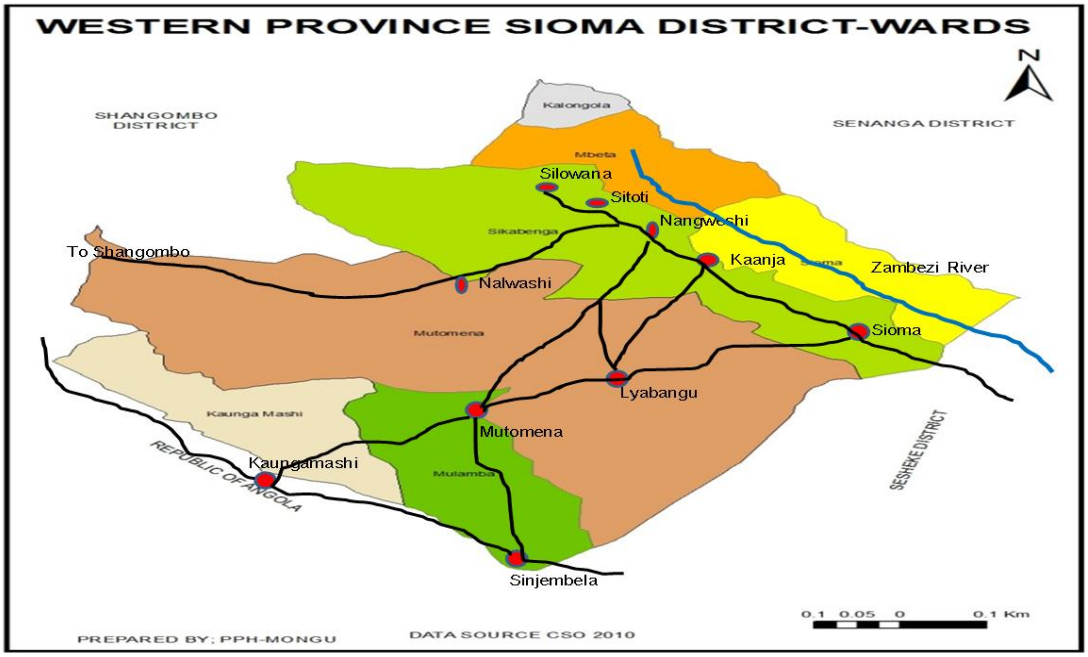

Figure 2. ***Map of Sioma District Showing Health Facilities; Source:*** *Sioma District Action Plan 2020 – 2023*

3.2 Study design

This is a retrospective cohort study, from period February, 2020 to February 2023. (Nickson, 2020) This is the systematic quantitative method of collecting information by reviewing pre-existing data of a sample of an individuals as well as the use of the administered research questionnaires to HIV defaulters. Since the study sought to establish the degree of relationship between the factors to HIV retention and the outcome in association with the following variables; patients' level of education, income, stigma, religious beliefs, mobility due to employment, side effects of the medicine and comorbidities. An observational study design produced statistical information about the significant of the factors affecting HIV treatment retention.

3.3 Study site and population/Research materials

The study population comprised of male and female living with HIV, in the age band 18 and 49 years who were once on ART and dropout of treatment over a period of time. According to the District Smartcare report and DHIS record, it is estimated that between February 2021 and February 2023, the district recorded about 475 patients who defaulted from the ART treatment.

The Zambia guidelines on ART treatments stipulates that an HIV patient is considered to have dropped out of treatment if they miss clinical ART appointments for more than 30 days (MOH-Zambia, 2020). The second study population constituted Doctors, Clinical Officers, Nurses and support workers working in the ART facility, because they have the experience and amassed necessary knowledge about HIV patients as well as understanding the ART programs. These will be interviewed in a focus group discussion in 4 selected Health Facilities.
Clients less than 18 years old and those above 50 will be excluded from the study

3.4 Selection of participants, sampling methods and sample size

Simple random sampling was used to select HIV clients who were once on ART treatment but have defaulted from the ART program over time. (Sikazwe I E.-W. I., 2019)The simple random technique is recommended by literature to be useful in studies with small samples as it tends to produce representative samples. (Lau & Kuziemsky, 2016).

The respondents were drawn from the list of HIV patients registered at Sioma UHC, Sitoti RHC, Nangweshi RHC and Kaunga Mashi RHC ART clinic respectively via randomized method, using Microsoft Excel 2019 after been exported from the cohort ART and the event registers.

Between April 2020 and February 2023, the district recorded 475 patients who defaulted from the ART treatment in the four selected facilities. (Smartcare, 2023).

Then, STATA Kaplan Meier formula was used to generate a sample size, as this was considered suitable for determining an appropriate sample size. The number of necessary subjects was estimated under the assumption that the proportion of the <studied parameter> would be 95.0%. With a type 1 risk of 5.0%, a Kaplan Meier test and a dropout rate estimated at 20.0%, 457 participants were estimated.

Randomly selected participant who declined to participate in the study, their numbers were removed from the sampling frame and a replaced by other respondent who also randomly selected.

3.5 Data collection plan and tools

The study used both primary and secondary data collection techniques using a quantitative tools to collect data from health facilities and all data that has been submitted to the DHO from the health institutions in the district to facilitate HMIS database, review of records from existing or previous researches, reports from Ministry of Health and review of Data from Sioma District

Health Office, Retention review reports, interviewing of health workers in the district and HIV positive clients in the district, among others.

A set of research questionnaires with both open and closed ended questions were developed and used to collect data via interviews to those who were unable to write, while those who were able to write filled in the questionnaires. HIA2 reports and data will be collected and analyses from the DHIS and HIMS from the District Health Information Office.

I included open-ended questions to give room for respondents to express their views and opinions fully.

The research questionnaires in this study was pre-tested at Sioma District Health Office of Western Province by the research assistants, through face-to-face interviews with the sampled clients. The pre-test was done in order to test the time it takes to complete one questionnaire, check for issues of validity and chronological order of questions and to eliminate issues of bias.

3.6 Data management and storage

Paper based data was secured in a lockable cupboard with limited access to researchers only while the electronic data was secured in three gadgets with passwords, in case one gadget crashes, two backup gadgets had the same information which was also protected with passwords.

3.7 Data analysis plan

Quantitative data was summarized, cleaned and coded using Microsoft Excel 2019 and then, analyzed using the Kaplan Meier curves and Log-rank test using Statistical Software (STATA) and Statistical Package for the Social Sciences (SPSS) version 21.0 (R. Bucciardini, 2023) and Kaplan-Meier method only to estimate survival probabilities from 'Date of inclusion' until 'Date of Death' and their pointwise 95% confidence intervals. Statistical analysis was performed with EasyMedStat (version 3.24; www.easymedstat.com), software to analyse the outcome (survival rate) of HIV retention to ART after a period of time.

All questionnaires with missing answers were excluded from the data analysis. Efforts was made to ensure that all the sections in the questionnaire are filled in correctly by putting the researcher's contact details on the questionnaire for respondents to get clarifications.

3.8 Ethical considerations

The researcher study participants to participate in the study based on their own willingness. During the collection of data, the study take into consideration the ethics. Firstly, before conducting interviews, informed consent were obtained from the selected respondents verbally and in written form, Secondly the researcher ensured that the identity of clients and data collected from the respondents were held with utmost confidentially. In addition, the researcher endeavored to include only questions that were meant to improve the ART program. Ethical clearance was obtained from the University of Zambia Research Ethics Committee **(Ref number 3937/2023)** and further authorized by the National Health Research Authority **(approval number NHRAR-R-319/24/4/2023).**

CHAPTER FOUR

FINDINGS

4.1 Results Analysis and Findings

Out of 475 targeted respondents, a total of 398 questionnaires were distributed among HIV defaulter respondents were reached, while only 363 consented to be interviewed and responded. In Sioma District between 15th April, 2023 and 21st April, 2023. Out of the total number of distributed questionnaires, 363 were filled and collected. The 363 collected questionnaires were checked for missing sections and parts so as to remove those that had missing parts or sections. 3 questionnaires were found to have missing parts and/or sections and were removed from the data analysis, leaving only 360 correctly filled questionnaires.

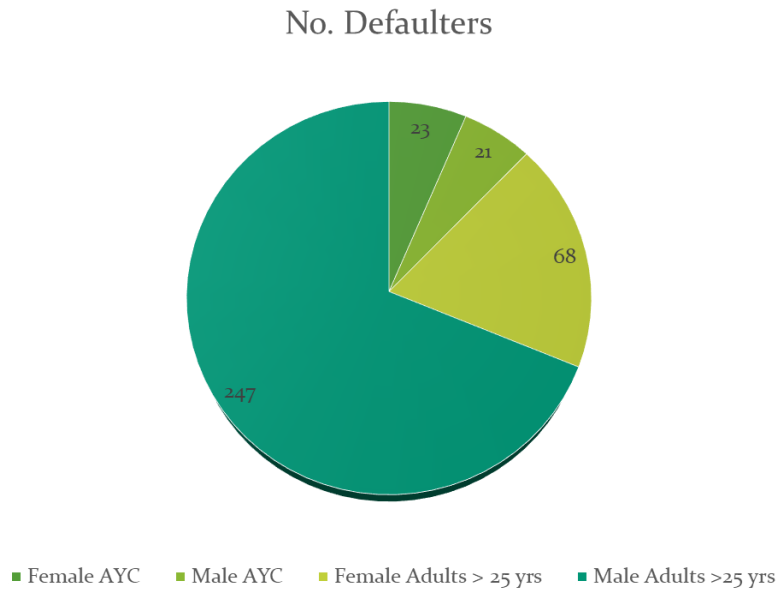

Figure 3. ***Results on Age and Sex Distribution***

Statistics	**Age at inclusion (years)**
N	360
Mean ± SD	32.2 ± 15.15
Min ; Max	2.02 ; 54.13
Median	30.92
Q1 ; Q3 (IQR)	19.51 ; 42.57 (23.06)

Table 1. Inclusion distribution

Demographic Date Analysis

Variable	Minimum	Maximum	Median (M)
Birth date	01/08/1965	01/11/2020	01/06/1989
Date of inclusion	19/09/2019	18/04/2023	18/03/2021
Date of Last Consultation	01/05/2021	01/05/2023	27/04/2023
Date of Death	03/06/2021	03/05/2023	27/04/2023

Numeric Analysis

Variable	Minimum	Maximum	Median (M)	Mean (μ)	Details
Progress (in %)	0	0	0	0	
Follow-up duration (months)	0.197	41.725	18.136	19.013	
Age (years)	33	45	40	39.333	
Age at inclusion (years)	2	54	31	32.308	
Age at last follow-up (years)	2	56	33	33.846	
Age at death (years)	2	56	29	32.2	
Year of inclusion	2019	2023	2021	2020.929	

Table 2. Mean Demographic data

4.2. Outcome results

Follow- up outcome	***n* (%)**
Total dropped out of care not reached/found	115(24)
Total dropped out of care reached and consented	360(76)
Health and able to work	26(7)
Sick and able to work	269(75)
Sick and unable to work	56(16)
Dead	9(3)
Total	**475 (100)**

Table 3. Survival outcome after defaulting ART

From the table above, it clear, that the majority of defaulted clients are having poor health outcome of which 3% passed on (dead). 75% were sick though able to perform minimal job while 16% cannot even perform any job as they were severely sick. The outcome suggests that there was great association between defaulting taking ARVs (poor retention) and poor health (morbidities and mortalities).

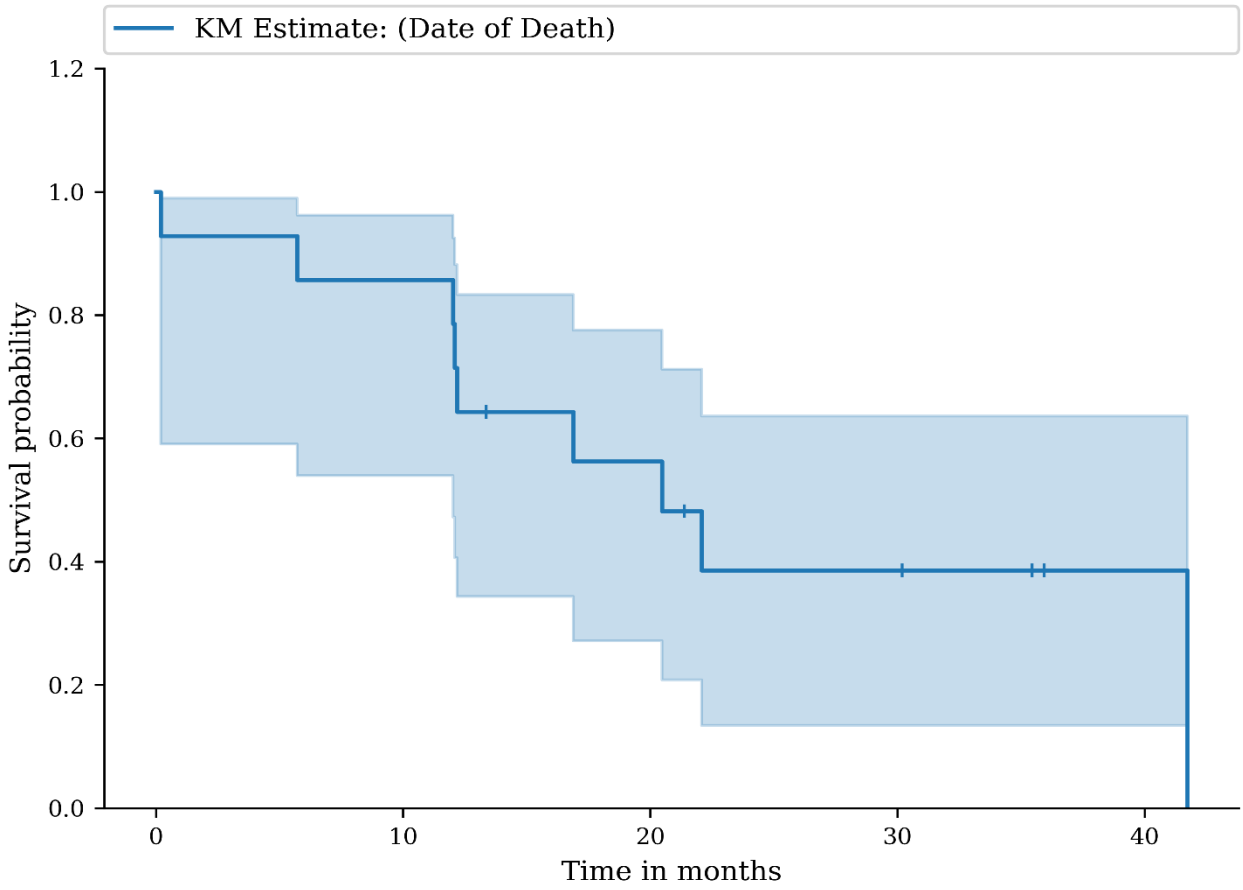

Figure 4. ***Survival outcome overtime using Kaplan Meier curve***

Months since dropped out from care	**Survival rate**	**95% confidence intervals**
0.0 month	100.00%	100.0%-100.0%
0.2 month	92.90%	59.1%-99.0%
5.7 months	85.70%	53.9%-96.2%
12.0 months	78.60%	47.2%-92.5%
12.1 months	71.40%	40.6%-88.2%
12.2 months	64.30%	34.3%-83.3%
13.4 months	64.30%	34.3%-83.3%
16.9 months	56.30%	27.2%-77.6%
20.5 months	48.20%	20.8%-71.2%

21.4 months	48.20%	20.8%-71.2%
22.1 months	38.60%	13.4%-63.6%
30.2 months	38.60%	13.4%-63.6%
35.4 months	38.60%	13.4%-63.6%
35.9 months	38.60%	13.4%-63.6%
41.7 months	0.00%	0.0%-0.0%

Table 4. Survival rate with Confidence interval of 95% over time

The median duration of follow-up was 18 months (0-41). At 12 months, the Date of Death-free survival was 85.7% (95% CI: 53.9-96.2) and at 24 months, the Date of Death-free survival was 38.6% (95% CI: 13.4-63.6).

Total Defaulters	Time	Died	Survived	s(t)
0	0	0	360	1
24	3	0	360	1
27	6	0	360	1
69	8	1	360	1
102	12	5	359	0.997222
132	15	1	354	0.983333
146	18	0	353	0.980556
170	21	0	353	0.980556
197	24	0	353	0.980556
204	27	2	353	0.980556
261	30	0	351	0.975
321	33	0	351	0.975
360	36	0	351	0.975
360	36	9	351	0.975

Table 5. Overall Survival rate

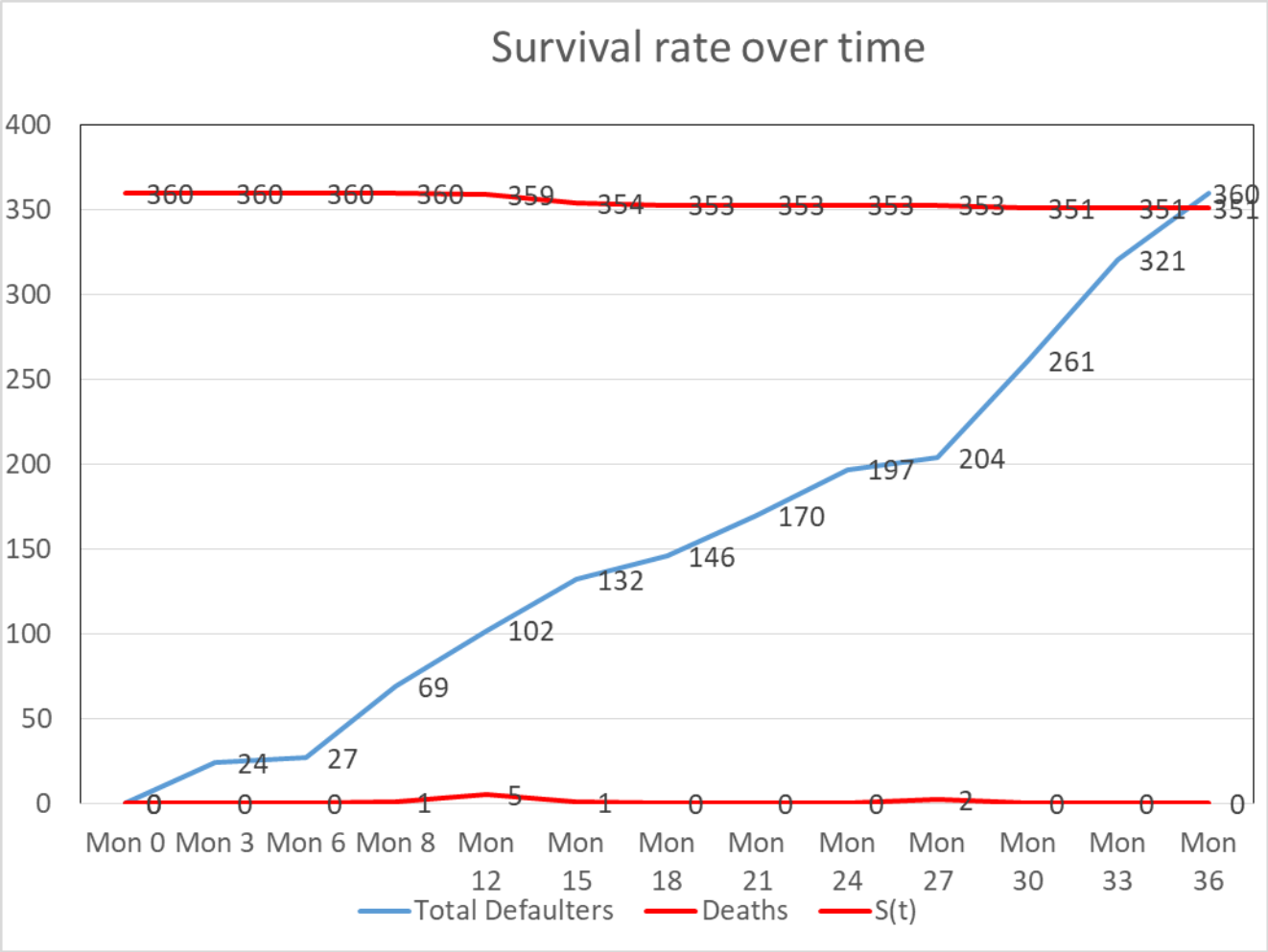

Figure 5. Death Survival rate run chart

We are able to appreciate that survival rate for HIV defaulters reduced over time, as the defaulter rate increased over time. Most of the mortalities 67% (n=6) occurred within 12 months after stopping taking ARVs. This applies to the increase in the occurrence of Opportunistic Infections (OIs) over time after clients stopped taking ARVs.

Most of them developed OIs 93% (n=313) within 12 months, all 100% of mortalities were associated with OIs.

Follow- up outcome	**n(%)**
Total dropped out of care reached and consented	360(100)
Health and able to work	26(7)

Total Sick	334(93)
Total developed OIs	313(93)
Total Death due to Ois	9(3), (100)
Total	**360 (100)**

Table 6. OIs outcome overtime

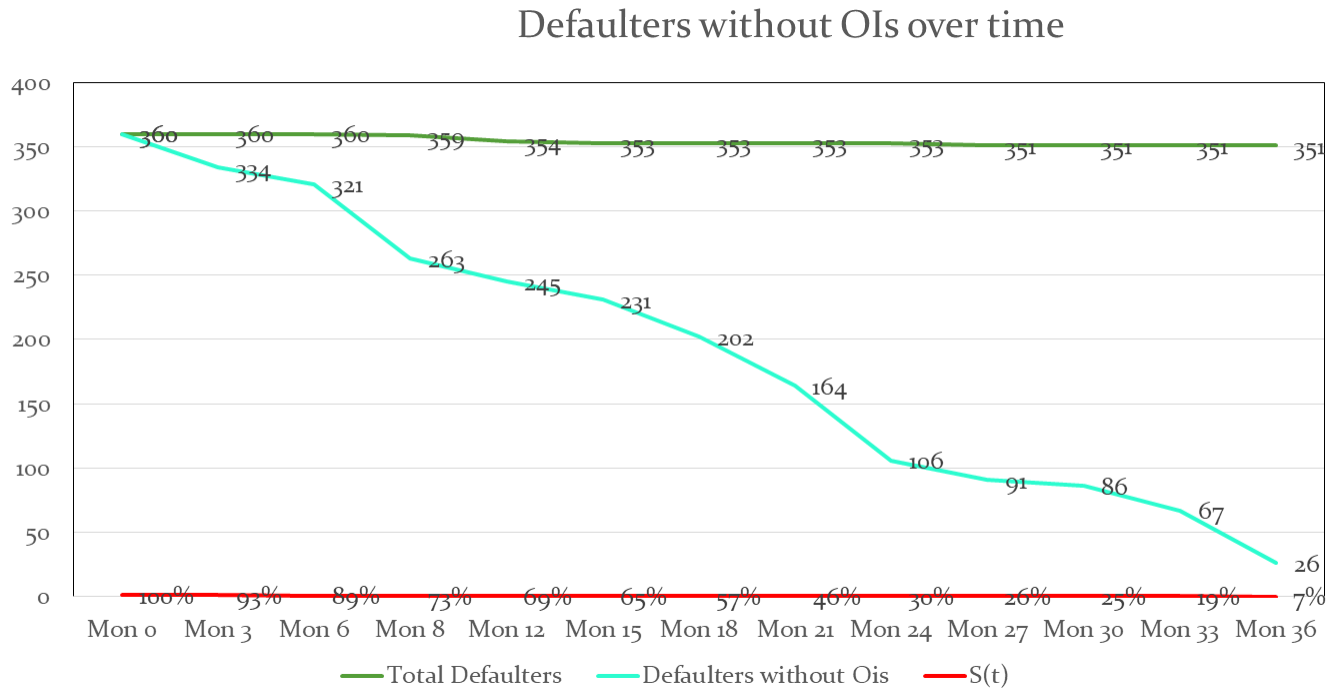

Figure 6. OIs run chart

Month Cohort	Total Defaulters	Defaulters without OIs	S(t)
Mon 0	360	360	100%
Mon 3	360	334	93%
Mon 6	360	321	89%
Mon 8	359	263	73%
Mon 12	354	245	69%
Mon 15	353	231	65%

Mon 18	353	202	57%
Mon 21	353	164	46%
Mon 24	353	106	30%
Mon 27	351	91	26%
Mon 30	351	86	25%
Mon 33	351	67	19%
Mon 36	351	26	7%

Table 7. OIs outcome overtime

4.2.1 Social Demographic Variables

Majority (69%, n=247) respondents were adult males above 25 years, adult female were few (19% n=68) and 45 adolescents and young people defaulted due to several factors.

The table below shows the social demographic data captured.

Variable	Sub-variable	Number of respondents (n)	%
Gender	Male	268	74
	Female	92	26
Age	24yrs & below	45	13
	25yrs – 30yrs	121	34
	31yrs – 40yrs	173	48
	Above 40yrs	21	6
Marital status	Single	61	17
	Married	210	58
	Widowed	9	3
	Separated	41	11
	Others	39	11
Religion	Christian	341	95
	Islam	0	0
	Traditional religions	19	5
	Non-religious	0	0
Level of education	Never attended school	38	11

	Primary	274	76
	Secondary	47	13
	Tertiary	1	0
Employment	Formal Employment	5	1
	Informal Employment	273	76
	Not doing anything	82	23

Table 8. Demographical table

The data shows clearly that most defaulters were not in formal employments though are married (58%), who most of them attended primary education only with 0% tertiary.

4.3. Factors contributing to retention in ART results

4.3. 1. Geographical and sociocultural factors contributes to poor retention

62% (n=214) of all respondents stopped taking ARVs because of long distance (> 12 KMs) for drug pickups, while 6% (n=25) was due to floods and cut off reasons.

The remaining 6% (n=23) stopped the ARVs because of fear of the husband and religious reasons. All were female adults.

Follow- up outcome	**n(%)**
Total dropped out of care reached and consented	360(100)
Total dropped out due to geographical factors	239(66)
Total dropped out due to long distance > 12 KMs	213(89)
Total dropped out due to floods/difficulties to cross Zambezi river	26(11)
Total	**360 (100)**

Table 9. Geographical factors to retention (responses)

Generally, geographical factors were the major 66% (n= 239) contributing factors to poor retention in sioma District among all the factors that were been studied on, of which long 89% of all dropped

out clients were unable to continue taking ARVs because they could keep up with what they were terming the journey of punishment for drug collection. Hence, decided to discontinue taking ARVs.

11% (26) under geographical factors stopped taking ARVs because it was always very hard for them to cross the Zambezi River for drug pickups during rainy season and floods. Hence, they opted to stop taking ARVs.

Follow- up outcome	**n(%)**
Total dropped out of care reached and consented	360(100)
Total dropped out due to sociocultural factors	23(6)
Total dropped out due to fear of the sexual partner to know	17(74)
Total dropped out due to religious reasons	6(26)
Total	**360 (100)**

Table 10. Sociocultural factors to retention (responses)

Though, sociocultural factors seemed not be the major contributing factors to poor or low retention in Sioma District compared to the other factors, the majority of the sociocultural contributing factors (74%) was stigma and fear of their sexual partners to know their HIV status, with the view that if their partner discovers that they are on ART, they will lose their marriage and support.

4.3.2 To determine medical conditions contributing factors to poor retention in ART

25 respondents suffered from covid once and 80% (n=20) ARV-Covid association, 70% (n=194) male adults were drunkard, 1% (n=5) had MDR TB. 11% (n=38) had hypertension, hence they stopped taking ARVs as they associated to HTN.

Follow- up outcome	**n(%)**
Total dropped out of care reached and consented	360(100)
Total defaulters who are alcoholic	194(54)

Health and able to work	26(7)
Total dropped out because of Sickness	67(19)
Total suffered from Covid-19	25(7)
Total dropped out because of Covid-19	20(80)
Dropped out because of TB/MDR	5(1)
Dropped out because of HTN/Stroke/CVA	38(11), (58%)
Dropped out because of other medical conditions	4(1)
Total	360 (100)

Table 11. Medical Conditions associated with poor retention in ART care

Generally, medical conditions factors contributed 19% (n=67) to poor retention in ART among all the drop out clients. Of which Cardiovascular conditions were the major (58%) contributing conditions followed by Covid-19, amounting to 30%.

To note, is that, 54% (n=194), were drunkard usually been taking locally made alcohol among all the defaulter.

4.3.3 To determine health system factors affects Retention in care for HIV positive Clients on ART

3% (n=12) …was taking long to see them and give then drugs each time they visited the facilities for drug pickups. Time wasting

12% (n=47) clients were told to make a queue outside the ART room as they are waiting for drugs. Lack of confidentiality

While 2% (n=8) experienced low libido, headache and insomnia. Drug Side effects

Follow- up outcome	**n(%)**
Total dropped out of care reached and consented	360(100)
Total defaulters who complained of long waiting time	93(26)
Waited for less than 30 minutes before been attended to	45(48)
Waited for more than 30 minutes before been attended to	21(23)
Waited for more than 1 hour before been attended to	27(29)

Total dropped out because of long waiting time over 1 hour	12(13), 3%
Total	**360 (100)**

Table 12. Long waiting time association to retention in ART

Follow- up outcome	**n(%)**
Total dropped out of care reached and consented	360(100)
Total defaulters who complained of Health System factors	67(19)
Dropped due to Long waiting time	12(18)
Dropped due to lack of confidentiality	47(70)
Dropped due to side effects	8(12)
Dropped due to stock unavailability	0(0)
Dropped due to staff shortages	0(0)
Total	**360 (100)**

Table 13. Health Care Systems association to retention in ART

The health systems factors contributed to 19% (n=67) dropout rate among all the factors, of which 70% dropped out of care as the result of lack of confidentiality at the facility, as the clients were subjected to queue up outside the ART rooms as they are waiting for clinicians to attend to them, of which a lot of people were able to see them waiting for the clinicians to seem them. While 12% of all the clients who dropped out of care under health systems factors were as the side effects like low libido, insomnia and headache each time they took their ARVs. Hence, they associated their headaches and insomnia to ARVs, which prompt them to stop taking ARVs.

CHAPTER FIVE

DISCUSSIONS

5.1. Introduction

The purpose of this research study was to explore the factors affecting retention in care of HIV/AIDS patients on ART program in the Sioma district. The objectives of the study were to: 1) determine the geographical and sociocultural factors that influence retention in care of patients on ART program in the district, 2) determine the medical condition factors that influence retention in care of patients on ART program in the district and 3) determine the health systems factors that influence retention in care of patients on ART program in the Sioma district.

The study found factors that influence patient retention in care which are diverse in nature and belonged to a wide spectrum of factors which include structural, medical and pandemics, social, health system and geographical related factors.

The study also evaluated how each factors contributed to poor retention in ART and the survival outcomes of poor retention which was generally poor.

5.2. Health Systems – Related Factors

Health system related factors included side effects to ARV drugs, weight increase and feeling better as a sign of good health. The findings of this study are consistent with the findings of Musheke et al. (Musheke, 2023).

The majority of respondents discontinued the treatment due to insomnia, headache and low libido, as they related these clinical pictures to the ARVs. Therefore, patients need to be encouraged to remain in care despite drug side effects. Intensive counseling on taking ARVs in the morning to respondents with insomnia issues, while those with headache and low libido to see the have balanced diets and medical checkups, should be employed in order to increase ART knowledge levels.

5.3. Sociocultural Factors

Some patients and health care workers reported stigma to be a hindrance to the long term retention of patients into care. The other factors that emerged as hindrances to adherence and retention in care for patients on ART treatment include use of traditional healers with herbal remedies, faith healing and beer drinking including non-disclosure of HIV status. People living with HIV fear to lose their social and emotional support by disclosing their HIV status to their spouses, social network or other family members for fear of marriage break down. (Mwale, 2017) The results of

this study are similar to those of other qualitative studies in developing countries. For example, a study conducted in Zambia by Musheke et al. (Musheke, 2023)reported feeling better, use of herbal remedies and faith healing as factors contributing to poor retention.

In this study, the major factor that stood up family under sociocultural factors was the fear of their sexual partners to know that they are taking ARVs, hence they opted to discontinue taking the ARVs before their partners discovers. However, when social support is threatened by involuntary disclosure of HIV status, individuals abandon treatment as a protective mechanism. Therefore, unless stigma and discrimination are confronted, patients on ART treatment are likely to discontinue the life drugs within 3 months after initiating them on ART, and hence compromise long term retention in care.

5.4. Geographical Factors

Since the beginning of ART care, the health sector have tried many support strategies to improve adherence and long term retention in care. Nevertheless, there are other natural phenomenal that the system have little or control over, for example, long distance from the facility to their villages and difficulties crossing the Zambezi river for some clients to access the health facilities. Making it very difficult for them tom continue taking ARVs disputed them wanting to continue taking ARVs. This was discovered to be the major factor contributing to poor retention in ART in Sioma District, as almost all the patients interviewed and health care workers reported long distances from the villages to the facility which is over 12 to 130 km.

The study by Mwale et..al 2017, agrees to this study that, travel distance to ART health facilities and transport cost was reported as a factor contributing to non-retention of patients in care. This is mostly because ART centers are sparsely distributed within the Kabwe district. In some instance, health care workers reported to have donated transport money to enable patients' access third line treatment in Lusaka. As a result, patients opted to transfer themselves to the nearest facilities to try and reduce on transport costs. Similar studies from Uganda (Mugisha et al., 2009) and Malawi (Geng, 2022) also found distance to ART centers as barrier to patient retention.

From these findings, the study suggest that ART clinics have to be brought nearer to the patients' homes as per the Zambian health vision of bringing services close to the family as possible, if we are to achieve the emergency plan goal of maintaining people on ART with lifelong retention for optimal viral suppression and clinical outcome. This would also make ART more accessible and would address some of the loss to follow up. The short term interventions that should be focused

on now are to intensify home drug delivery and ensure that these respondents are given 12 months drug dispensations (12 MMD) from 6 MMD.

5.5. Medical Conditions Factors

Medical conditions such as Covid-19, Hypertension (HTN), Stroke, Tuberculosis (TB), MDR, drug/substance abuse were the root causes to why over 67 respondents stopped taking ARVs. AS most of them were associating their comorbidities to ARVs.

5.6. Limitations of the study

Though, measures to ensure trustworthiness and representativeness of the study, the findings of the study were limited in a number of ways. There was a possibility of the participants giving false responses due to the sensitivity of the study topic involving HIV and AIDS, thereby affecting the results. To overcome this, the participants were reassured of confidentiality. The sampling process of participants to reach the desired number was another limitation of this study. Some patients transferred themselves from the clinics without knowing where they had transferred to. This made it difficult to follow them up. The number was reached because of nurses and adherence support workers who are better placed to identify information-rich cases. Unforeseen work related activities, especially field works.

Other several limitations arose during the time this study was carried out. The study had a number of many participants drop out of the study due to other engagements while ,others were Namibian and Angolan clients and thus reduced the sample size from the projected 475 to 390 thereby reducing the representativeness of the sample. Some respondents wasn't comfortable interviewing them in their homes, due to stigma, hence we opted to administer the questionnaires to such respondents in the nearby school offices in their local areas, while it was also a bigger challenge to follow up clients who were coming from the other side of the village which is across the Zambezi River. Language barriers also paused as a challenge to respondents who were unable either speak or ready English, Nyanja, Lozi or Tonga.

Another limitation is the fact that this study was a retrospective study to determine factors associated to retention and the outcome but did not address on the interventions to address factors associated to poor retention and it long term impact to clients, the family and the country at large.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Since the commencement of ART, ART retention in Africa have been the major issues that UNAIDS is supporting to ensure that it goes and maintained at 95% and above. The ART retention rate for Sioma District is about 89% of their patients at the end of three years on ART as a lot are considered as lost to follow-up or defaulters mainly due to geographical, sociocultural, medical conditions and Health system factors. The findings of this study suggest that low retention rates are an indicator of major weaknesses in the support system around the patient and is attributing to lower surviving rate in HIV positive clients. The study has answered all the research question and established that the poor retention in ART in the district of Sioma is mainly because of long distance from the facility to their villages which is a huge cost for them to book an ox-cat for transportation.

These respondents have hence worsen their health further by stopping ARVs as most of them were in HIV WHO stage 3 and 4 respectively.

The program resources could also be scarce to build more clinics in farfetched areas or to buy boats to helping clients cross the Zambezi River during rainy season. Therefore, there may be need to address the underlying factors of non-retention in care of patients on ART program taking into account that, every single patient who is retained in care and on ART is a life saved and potentially a source of tremendous benefit to the family, community and the nation at large.

6.2. Recommendations

6.2.1. Recommendations on the Health System Factors

Some clients reported to have stopped ARVs due to long waiting time, let's ensure that stable clients are fast tracked and seen in confidential and secure ART room each time they visit our facility to reduce on congestion and time wasting. While others were as the result of lack of confidentiality at facility level, therefore let's ensure that there is availability of confidential ART waiting rooms which can be improvised at facility level or the government to provide ART refurbishment rooms.

6.2.2 Recommendation on medical conditions factors

Some respondents dropped out of care because of NCDs which could have been associated to high alcohol consumption. While other patients were reported to have defaulted on treatment after registering great improvement in their health. Indeed, many HIV positive persons were reported to have resorted to heavy alcohol consumption and this alcoholism impact negatively on their adherence and retention in care in the long run, therefore, I recommend NCDs screening to all ART clients whenever they visit the facility for drug pickups. Those with existing condition must be put on treatment as soon as possible.

Covid-19 was associated with poor retention, hence, there is urgent need to educate the community and the recipient of care that ARVs does not cause Covid-19, instead it helps prevent one from acquiring the Corona Virus by means of improving the client's immune system.

Clients with TB/MDR co-infected must be well isolated and considered as special clients, treat them for TB, and put them nutrition care package. Ensure that all recipient of care are screened for TB each time they visit the facilities for drug pickups, those screened negative should be put on TB preventive therapy for 6 months. While those screened TB positive must submit sputum for Gene Xpert.

6.2.3 Recommendation on Geographical and sociocultural factors

Majority of the clients drooped out of care because long distance, these clients must be followed up and offered intensive and consistence adherence counselling on the goals/benefit of ARVs and put them on 6 MMD. The government to consider the introduction of 12 MMD as well as the establishment of Community ART corners in all farfetched villages.

Intensify mobile ART to reach out to farfetched clients with drug pick up challenges and those coming from across the Zambezi River.

Some clients reported to have stopped ARVs because of Stigma and fear of their sexual partner. Encourage Provider initiated disclosure to help the partner to disclosure their HIV status to their partners. In a long run, I urge the government to introduce injectable ARVs for 6 to 12 months. If retention of above 95% is to be achieved.

Educate the community and the recipient of care that HIV has no cure, no matter your religion faith, therefore, adherence is key.

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APPENDICES

Research Timelines

NO	Task to be Performed	Dates	Personnel Assigned	Person Days
1	Finalize Research Proposal	5th April, 2023	Principal Researcher	2
2	Submit to ethics – HOD- UNZA	7th April, 2023	Principal Researcher	3
3	Approval by NHRA/Ethics	9th April, 2023	Principal Researcher	1
3	Data collection	10th April to 15th April, 2023	Research Team	4
4	Data analysis	16th to 30th April 2023	Research Team	20
5	Oral defense and submission	May, 2023	Research Team	1
6	Graduation Ceremony	May, 2023	Principal Researcher	1

Budget

S/N	Budget Item	Unit Cost	Multiplying Factor	Total Cost
1	Photocopying Questionnaires	2	170	340
2	Photocopying consent form	1	160	160
3	Transport To HF and HP	50	20	1000
	To Mini hospital	50	1	50
4	Printing Report	100	5	500
5	Binding Report	50	3	150
6	Principal Researcher: Meal	50	50	2500
	Project Allowance	1000	1	1000
8	Contingency	200	1	200
	TOTAL			**5900**

Justification of Budget

2.2 Tools

170 questionnaires and 170 consent forms will be needed of which 160 will be used to collect data and 10 for testing the questionnaire and for contingency in case of damage or loss. It is important to have an adequate number of extra questionnaires and consent forms as the data collection will be done out-doors making the tools susceptible to damage and loss.

2.3. Transportation

Transportation costs cover two return trips to the five different proposed sites for data collection. Two days will be spent at each site. Taxis will be used to avoid damage or loss of the tools and to ensure confidentiality of the materials during transportation.

2.4. Report

5 copies of the report will be printed. The first will be a draft and will be submitted to the supervisor for possible correction of errors. The next 3 copies will be versions of the final report and will be submitted to the concerned parties. These final 3 copies will be sent for binding.

2.5. Principal Researcher

The Principal Researcher will receive a daily allowance of K 50 to be used for meals during the 50days working schedule. A project allowance of K 500 will be given for the work.

2.6. Research Assistants

The Research Assistants will receive a daily meal allowance of K 50 to be used for meals during Training, Data Collection and Data entry. A project allowance of K 500 will also be given for the hard work.

2.7. Contingency

A contingency fund of K 200 will be used for any eventualities that might arise.

Participant Information Sheet

Project Title: Determine Factors to Retention in Care of Participants on Antiretroviral Treatment in the Sioma District, Zambia.

Principal investigator: My name is Jones Lyuba. I am a student studying Masters in Public Health at the University of Zambia. I am working in Zambia for a non-governmental organization called CDC-Zambia.

Invitation: I am inviting you to participate in this research study which is a partial fulfillment of the requirement for the degree master of Public Health. I am gathering information from patients like you who are 18 to 49 years old and have discontinued taking ARV treatment or are still taking the treatment. I am trying to determine how the various factors such as health system, individual, social and structural factors affect retention of patients on ART program in the Sioma District. Please read the following information carefully, thereafter take time to decide whether to participate or not. Your reading of this information will be highly appreciated.

What is this study about?

The purpose of the study is to gain insight into the challenges or problems HIV and AIDS patients face whilst on Antiretroviral Therapy. It is hoped that with your participation, an understanding of the factors that are affecting retention of patients in ART program will be identified which can help in the development of ART programs which are tailored to the needs of patients and may be efficient in increasing patients' retention on the ART program in the district.

What will I be asked to do if I agree to participate?

You will be asked a number of questions which will only take a few minutes of your time. The questions will be on the following issues: reasons patients who start ART decide to discontinue treatment later on, experiences and challenges patients face whilst on treatment and what you think can be done to ensure patients who start ART do not discontinue in the long run. The interview will take place at your clinic/place of work.

Would my participation in this study be kept confidential?

All your personal information will be kept confidential. To help protect your confidentiality, I will not put your name on the interview form but instead I will use codes (pseudonyms). An identification key will be used by the investigator to link the study to your identity and no one other than the investigator will have access to the identification key. The data forms and audio tapes will be secured in a lockable place at all times and will be destroyed after the study data has

been collected. Whatever information you give will not affect the care you receive from this clinic or relations you have in this clinic and the information will not be given to anyone. It will only be used anonymously in a report aimed at improving the ART program. If I write a report or article about this research study, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There may be minimal risks associated with participating in this research study such as psychological or emotional risks due to the sensitivity of the research topic. Should this happen, emotional support will be provided by making available a psychosocial counselor for you.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the factors that are affecting retention of HIV patients on
ART programs in the district. I hope that, in the future other people might benefit from this study through improved understanding of the health needs of people living with
HIV/AIDS including those on ART program. The anticipated benefit to the science is knowledge concerning the exploration of ART programs for people on ART and factors contributing to low retention rates of patients in ART program in Sioma district.

Do I have to be in this research and may I stop participating at any time?

Participation in the study is completely voluntary. You may choose to participate or not to participate. You are free to withdraw should you wish to discontinue with the interview and this will not affect you in any way and you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

If you have any questions about the research study itself, please contact Mr Jones Lyuba at: WPHO/CDC- Zambia. P.O Box 920068, Kaoma DHO. Cell
Phone: +260 965475117/+260 970797308; Email: joneslyuba@yahoo.com or joneslyuba@gmail.com

Should you wish to report any concerns or problems you have experienced related to the study, please contact: The University of Zambia Research ethical committee

OR my project supervisor

Dr. Cosmas Zyambo, UNZA- School of Public Health

Consent and Introduction

Hello. My name is _____. I am a student at the university of Zambia-UNZA. I am pursuing a master's degree. As part of the fulfilment of the requirements for the degree of Public Health, I need to submit a thesis. Therefore, I am conducting a study on the factors affecting retention in care of patients on antiretroviral treatment in Western Province. You have been randomly selected to participate in this interview. Your responses will be treated with highest degree confidentiality. The information collected is purely for the purpose of this study. Your participation will be highly appreciated.

Do I have your permission to continue?

For further information about the study

Dr. C. ZYAMBO (MPH HOD)
School of Public Health
Ridgeway campus
Lusaka, ZAMBIA.
Cell No. 0977998803

I agree to participate in this study.

Participant's Signature: _____ Date:_____

Research Questionnaire

Date: …… **Questionnaire No.: ……**

1. Demographic variables:

2. Age (in years): _____

3. Sex: 0= M 1= F

4. Marital status: 1=Married 2= Never married 3=Widowed 4=Divorced 5=Separated

5. Level of education; 1=None 2=Primary 3=Upper Primary 4= Secondary 5=Tertiary

6. Occupation: 1=Unemployed 2=Salaried employee 3=Farming 4=Casual works 5=other

7. Average household monthly income_____

8. Information regarding the clinical condition of the patient

8.1 Period taken since diagnosed with HIV infection? _____

8.2 Do you have any underlying Medical condition? _____

8.3 If yes kindly specify the underlying condition you have _____

8.4 How long have you been started on antiretroviral treatment? 1= Less than a year 2= 1-2 years 3= 2-3 years 4= 3-4 years 5=5 and more years

8.3 Were you sick in the last 30 days? 0=Yes 1=No

8.4. If yes to Q8.2; how serious was your sickness? 1= Mild 2=Moderate 3=Severe 4=Very severe

9. Questions related to HIV drugs and adherence

9.1. Type of current ARV regimen?

I. Name of ARV regimen

II. No. of pills each time

III. Morning or Evening or both

10. ARV drugs that the patient may have missed taking over the last seven days.

I. Names of your ARV

II. Medications

III. Doses missed in the last seven days

10.1. Schedule for taking ARV 1=Once 2=twice 3=three times

10.2. How closely did you follow your timetable over past 7 days? 1= about half of the time 2= Most of the time 3=Some of the time 4=Never

10.3. How often did you follow special instructions for taking ARV in last 7 days? 1= about half of the time 2= Most of the time 3=Some of the time 4=Never

10.4. People may miss taking their medications for various reasons. What were your reasons for missing any of your ART medications in the last 7 days.

1. being away from home
2. being busy with other things
3. simply forgot
4. having too many pills to take
5. wanted to avoid side effects
6. do not want others to notice taking medication
7. a change in daily routine
8. felt like the drug was harmful
9. felt sick or ill
10. felt depressed
11. ran out of pills
12. felt good
13. lack of transportation
14. shortage of food

15=others, specify _____

11. Knowledge about HIV disease and antiretroviral therapy

1. Very Poor 2. Poor 3. Average 4. Good 5. Very Good

13. The following questions ask about your social support.

13.1 Have you told your family members about your HIV status? 1=Yes 2=No

13.2 If yes to Q13.1, how satisfied are you with the support you receive from family/friends

1=very dissatisfied 2=somewhat dissatisfied 3=neither dissatisfied or satisfied 4=somewhat satisfied 5=very satisfied

13.3. How often do your friends and/or family members help you remember to take your medication? 1= About half of the time 2= Most of the time 3=Some of the time 4=Never

13.4. Do you use any ways to remind taking your ARV drugs? 1=Yes 2= No

14. Perception on patient provider relationship

1. Questions Strongly disagree
2. Somewhat disagree
3. Neither agree nor disagree
4. Somewhat agree
5. Strongly agree

14.1. The healthcare providers give suitable information about taking your drugs.

14.2. It is easy for you to discuss HIV related problem to your medication with the health care providers.

14.4. The healthcare providers understand the problems you may have taking your ARV medications.

14.5. The healthcare providers frequently help you in solving the problems you may have taking ARV pills.

14.6. You are satisfied with the overall support you get from the healthcare providers.

15. Clinical setting Questions Strongly

1. Disagree Somewhat
2. Disagree
3. Neither agree nor disagree
4. Somewhat agree
5. Strongly agree

15.1. You believe that health care providers keep your health-related information confidential.

15.2. You are convenient with the scheduling appointments to your medication refill.

15.3 You have encountered frequent missed clinic appointments due to floody.

15.4 You have encountered frequent missed clinic appointments due to long distance.

15.5 You have encountered frequent missed clinic appointments due to lack of transport money.

15.6 You have encountered frequent missed clinic appointments due to Hang over.

15.7 You have never got a problem to your medication refill related to ARV drug supply.

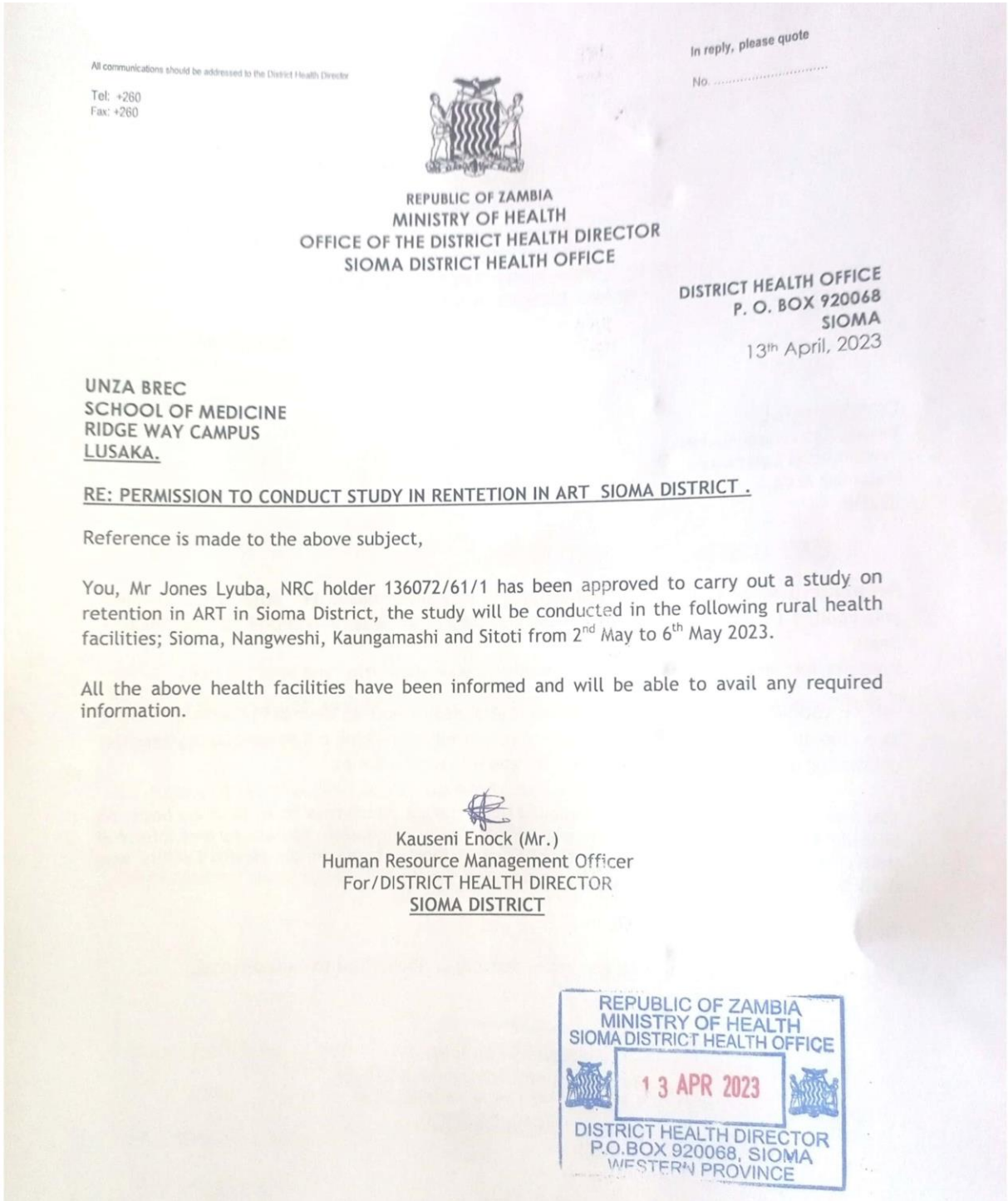
15.8 You are well satisfied with the overall health care services delivered by the health facility.

16. People have various health habits. The following questions ask about your alcohol and drug use, past and current.

16.1. Have you ever had a drink containing alcohol? 1= Yes 2= No, if yes, have you had a drink within the last 30 days? 1= Yes 2= No

17.2. Have you ever smoked cigarette? 1= Yes 2= No, if yes, have you smoked within the last 30 days? 1= Yes 2

Permission Letter



All communications should be addressed to the District Health Director

Tel: +260
Fax: +260

In reply, please quote

No. .....

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
OFFICE OF THE DISTRICT HEALTH DIRECTOR
SIOMA DISTRICT HEALTH OFFICE

DISTRICT HEALTH OFFICE
P. O. BOX 920068
SIOMA
13th April, 2023

UNZA BREC
SCHOOL OF MEDICINE
RIDGE WAY CAMPUS
LUSAKA.

RE: PERMISSION TO CONDUCT STUDY IN RENTETION IN ART SIOMA DISTRICT .

Reference is made to the above subject,

You, Mr Jones Lyuba, NRC holder 136072/61/1 has been approved to carry out a study on retention in ART in Sioma District, the study will be conducted in the following rural health facilities; Sioma, Nangweshi, Kaungamashi and Sitoti from 2nd May to 6th May 2023.

All the above health facilities have been informed and will be able to avail any required information.

Kauseni Enock (Mr.)
Human Resource Management Officer
For/DISTRICT HEALTH DIRECTOR
SIOMA DISTRICT

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
SIOMA DISTRICT HEALTH OFFICE
13 APR 2023
DISTRICT HEALTH DIRECTOR
P.O.BOX 920068, SIOMA
WESTERN PROVINCE

Research License

NATIONAL HEALTH RESEARCH AUTHORITY

The Health Research Act

(Act No. 2 of 2013)

MINISTRY OF HEALTH

CERTIFICATE OF REGISTRATION

THIS IS TO CERTIFY THAT

Lyuba Jones

has been registered as a Health Researcher

Dated this 25th April 2023

Registration NHRAR-R-319/24/04/2023

DIRECTOR

PROF. GODFREY BIEMBA