

**FACTORS AFFECTING RETENTION IN CARE OF  
PATIENTS ON ANTIRETROVIRAL TREATMENT  
IN THE KABWE DISTRICT, ZAMBIA**

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A mini-thesis submitted in partial fulfilment of the  
requirements for the degree of Master in Public Health at  
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## KEYWORDS

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## ABSTRACT

**Introduction:** HIV and AIDS continues to be a major public health challenge for Zambia, which has the highest HIV prevalence rate of 13.1% in sub-Saharan Africa. Although individuals living with HIV/AIDS in Zambia have increased access to antiretroviral treatment (ART), 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. The current study aimed to explore the factors affecting retention in care among patients receiving antiretroviral treatment at three primary health facilities in the Kabwe district in Zambia.

**Methodology:** An exploratory qualitative study design was used to explore the patient, health systems and socio-economic factors that underlie retention on ART in three purposefully selected primary health care facilities in Kabwe district. Data was collected through in-depth interviews with 45 ART patients and three focus group discussions with 20 health care providers. The content of the transcribed interviews was analyzed thematically.

**Findings:** The overall retention rate of the ART sites was found to be 65%. The main patient factors that influenced retention in care were side effects of antiretroviral drugs and weight increase as a sign of good health. The social related factors that influenced patient retention in care were stigma and non-disclosure of HIV status, faith healing, use of herbal remedies and alcohol use. The health system factors that contributed to poor retention of patients in care were long waiting times due to staff shortage, high patient load, travel distance to ART centers and transportation cost. Other health system factors reported by participants included shortage of third line ARV drugs and inadequate space in ART clinic. Finally, food shortage and mobility of patients due to employment were some of the identified economic factors that influenced patient retention in care.

**Conclusions:** A large proportion of adult patients initiating ART in Zambia are poorly retained in care because of patient, health system, social and economic factors. In order to improve retention, more nurses and clinical officers should be trained in ART management to improve skills and address staff shortages. It would also be useful for

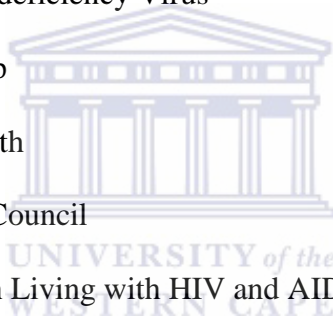
Zambia to introduce community drug distribution points for delivering ARV refills to reduce the workload on the existing ART sites and reduce on the distances that patients have to travel to ART centers. Additionally, efforts should also be made to improve ART care by extending ART clinic days to include all the days of the week except Sundays.





## ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CSO	Central Statistics Office
DHMT	District Health Management Team
HIV	Human Immunodeficiency Virus
LTFU	Lost to follow up
MOH	Ministry of Health
NAC	National AIDS Council
PLHA	People or Person Living with HIV and AIDS
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
WHO	World Health Organization
ZDHS	Zambia Demographic and Health Survey



## 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.

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

**Loss-to-follow-up:** The phrase, lost-to-follow-up, is frequently used in 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.

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**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.

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

## DECLARATION

I declare that this thesis entitled “*Factors affecting retention in care of patients on antiretroviral treatment in Kabwe district, Zambia*” is my own work. It has not been submitted for any degree or examination in any other university and that all the references I have used or quoted have been acknowledged.

Full Name: Joyce Chali Mwale



Signed:

Date: 21 June 2016

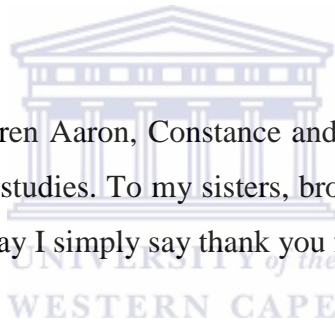


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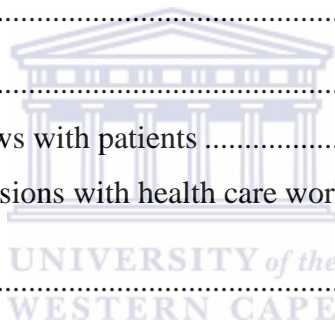
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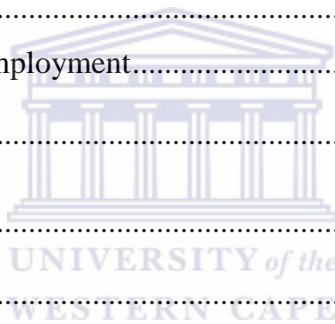
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# CHAPTER ONE – INTRODUCTION

## 1.1 BACKGROUND

HIV/AIDS remains a major public health problem across all continents, causing the death of millions of adults in their prime, disrupting and impoverishing families and turning millions of children into orphans (WHO, 2011). UNAIDS (2012) indicates that the pandemic affects the most productive segments of the populations. Globally, an estimated 36.9 million people were living with HIV (PLWH) by the end of 2014 (WHO 2015). Out of these, 2 million people were newly infected with HIV in 2014 (WHO, 2015). The sub-Saharan African region remains most affected, with 25.8 million living with HIV and accounting for almost 70% of the global total of new HIV infections (WHO, 2015).

According to UNAIDS, (2012), there has been a dramatic change in the global HIV/AIDS landscape because of increased attention to care, treatment and support. At the end of 2014, it was estimated that 14.9 million people living with HIV had access to antiretroviral treatment globally, of which 13.5 million were receiving antiretroviral treatment (ART) in low- and middle-income countries (WHO, 2015). During the 2014 world AIDS conference, UNAIDS launched an initiative called the '90-90-90' initiative for 2020 with the prospective to end the pandemic by 2030 (UNAIDS, 2014). This means that 90% of all people living with HIV should know their HIV status, 90% of all people with diagnosed HIV infection should receive antiretroviral treatment and 90% of those on ART should be retained in care and virally suppressed.

Zambia has a population of 13.3 million people (Zambia Demographic and Health Survey [ZDHS], 2013) and it is one of the Sub Saharan African countries worst hit by HIV and AIDS epidemic (UNAIDS, 2014). In Zambia, the HIV prevalence is estimated to be 13.1% (ZDHS, 2013). At the end of 2014, 1.2 million people were living with HIV, of which a million were adults aged 15-49 years and 540,000 women. HIV is the leading cause of death for all ages in Zambia. During the 2014 period, 19,000 people died due to

HIV/AIDS. The epidemic is estimated to have left at least 380,000 children orphaned (UNAIDS, 2014).

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

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

Despite the proven and documented benefits of ART (WHO, 2015; Franziska, 2011), retention of patients in most antiretroviral treatment programs continues to be one of the biggest challenges. A number of people living with HIV are lost at different times in the continuum of care. Many studies have shown that the proportions of patients that remain in care following ART initiation are low and retention in care remains a challenge in many countries with a high burden of HIV/AIDS (Franziska, 2011; Bucciardini et al., 2015). A review of 33 patient cohorts taking ART in 13 African countries suggested only

60% of patients remain in ART programs after two years with lost to follow up accounting for 56% of all attrition (Fox & Rosen, 2010).

## **1.2 PROBLEM STATEMENT**

The introduction of ART and its scale up has led to the improvement of quality of life of people living with HIV and AIDS in Zambia. However, patients who are initiated on ART do not adhere to treatment or remain in care. Evidence shows that more than 50% of patients discontinue treatment through death or lost to follow up (Scott et al., 2014). The service statistics for the Kabwe district (2011 – 2013) indicate that only 45% of ART patients are retained in care at 36 months after initiating treatment (Zambia Prevention Care and Treatment II [ZPCT], 2014). 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. Retention of patients in care, though recognized as a prerequisite for achieving any level of adherence, has received less attention. Retention in care of patients on ART program is of public health importance. Therefore, a better understanding of the factors affecting retention in care of patients on ART program in Zambia is needed.

## **1.3 AIM AND OBJECTIVES**

This study explored the factors affecting retention in care of HIV/AIDS patients on ART program in the Kabwe district.

The objectives of the study were:

- To explore the economic factors that influence retention in care of patients on ART program in the Kabwe district.

- To explore structural factors that affect retention in care of patients on ART program in the Kabwe district.
- To explore social factors that affect retention in care of patients on ART program in the Kabwe district.

#### **1.4 STRUCTURE OF THE THESIS**

This thesis is divided into five chapters. Chapter one gives the background to the research study including the study context and objectives. Chapter two presents a review of the literature on retention in care of patients on ART programs in Sub-Saharan countries including Zambia, factors affecting retention in care and strategies that may help to retain patients in care. The third chapter describes the methodology used in the study and the study setting. Chapter three also describes the study design, study population, and the sampling process employed to obtain the study sample, the data collection methods and analysis of data including rigor of the study as well as highlighting ethical issues and limitations. The fourth chapter shall present the findings of the research study. The fifth shall discuss the findings. The final chapter draws conclusions from the study and makes recommendations based on the findings.



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## **CHAPTER TWO - LITERATURE REVIEW**

### **2.1 INTRODUCTION**

In this chapter, the investigator explored the various definitions of retention in care and some concepts related to defining retention in care: attrition and lost to follow up. Thereafter, retention in care as used in this study is conceptualised. Then, the investigator explored the factors affecting patient retention in care globally, in sub-Saharan Africa and in Zambia. The investigator also focussed on various strategies that have been put in place to improve patient retention in care 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 (WHO, 2015), 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.

### **2.2 DEFINING RETENTION IN CARE, LOST TO FOLLOW UP AND ATTRITION**

*Retention in care* is complex, difficult to define and hard to measure (Mugavero et al., 2012). It has been defined as continuous engagement of patients in ART care (WHO, 2011). Other authors define retention in care as the proportion of patients alive and remaining in an ART program (Fox & Rosen, 2010; Geng et al., 2010). Both definitions suggest that being retained in care means remaining connected to care and keeping all scheduled appointments. Various methods have been used to measure retention in care in practical settings. Retention in care by Patel et al. (2010) is measured by attending regular follow up appointments to include scheduled laboratory tests and other monitoring

activities. In some industrialized settings, the frequency of visit to the ART clinic has been used as a measure of retention (Giordano, 2011). In Zambia, retention in care is being measured at some interval of time after a certain period of time such as after 6 months, 12 months or 24 months. Based on the interval used to describe patients as retained in care, patients are said to be lost to follow-up when they do not attend a scheduled appointment with the retention timeframe.

Programmatically, *Loss to follow up* refers to patients receiving ART who were more than 3 months late for a scheduled clinic or pharmacy visit and who were neither transfers-out nor relocations (MoH, 2014). It represents patients who have died, self-transferred to another facility and those who are alive but voluntarily withdraw from care. Zambia's National ART program defines loss to follow-up as missing scheduled appointments for three consecutive months (MoH, 2014).

On the other hand, *attrition* is the discontinuation of ART by patients through death, loss to follow-up, and stopping ARV medications while remaining in care. Attrition also include patients who are alive, but have transferred to other centres or have stopped ART due to a variety of reasons (Fox & Rosen, 2010; Tayler-Smith et al., 2011). 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. This is true especially in ART programs that lack capacity to trace and monitor patients outside the confinements of the clinic (Koole et al., 2013). 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 et al., 2012; Koole et al., 2013).

## **2.3 RETENTION IN CARE OF HIV PATIENTS ON ANTIRETROVIRAL TREATMENT**

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 (Fox & Rosen, 2010). However, studies on retention across Sub-Saharan Africa have come up with varying



results on retention rates and they have shown that not all patients remain on treatment; some patients decide to drop out of treatment programs (Geng et al., 2010). 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.

ART programs in African countries have retained about 60% of their patients at the end of two years on ART treatment (Fox & Rosen, 2010). A tracking study at a clinic in Mbarara in Uganda on patients lost to follow-up shows a 51% overall retention rate at 24 months with 29% of patients deceased (unregistered deaths), 10% alive, but not in care, 39% alive but of unknown care status (Geng et al., 2010). Studies from Ethiopia (Assefa et al., 2011), Malawi (Weigel et al., 2012), South Africa (Ahonkhai et al., 2012) and Zimbabwe (Mutasa-Apollo et al., 2014) all indicate that approximately one-quarter of patients are no longer retained in care after one year with loss to follow up and deaths being the main cause of attrition.

In Zambia, only 59% of patients on ART are retained in ART care at 24 months after initiation and 54% at 60 months after initiation (MoH/NAC, 2013). A quantitative study conducted by Malebe et al. (2014) in the rural part of Zambia's Mansa district of Luapula province, showed retention rates of 91%, 59%, and 52% at 12 months, 36 months and 60 months respectively. The lost to follow up and death were the main cause of attrition. Scott et al. (2014) argue that retention in care is still a challenge facing ART programs in Zambia and this needs the attention of both health care providers, Ministry of Health and Ministry of Community Development, Mother and Child Health.

The above mentioned retention rates show that patients on ART are poorly retained in ART programs; therefore, loss to follow up is a major challenge in HIV care. The reason could be that patient follow-up is limited to the clinic and health care providers lack the capacity to trace and support patients back on ART programs. In contrast, an observational study at two large HIV clinics in Vietnam by Matsumoto et al. (2015) reported better retention in care rates. The 12-month retention rate in this study was 95.3% with a low mortality rate of 5%. In this cohort, patients on an ART program were routinely traced once they missed an appointment by community-based counselors and

linked to appropriate care. Studies show that retaining HIV infected patients in care has the potential to help contain health care costs by improving HIV specific outcomes and reducing emergency department visits and hospitalization (Giordano et al., 2007; Mugavero et al., 2009). In addition, retention provides the opportunity to implement preventive health care interventions and to promote health behavior change that may decrease HIV transmission (Mugavero et al., 2009).

## **2.4 THE CONSEQUENCES OF POOR RETENTION**

While retention in care of people living with HIV initiated on ART has been shown to reflect individual treatment success, poor retention is associated with negative outcomes. These outcomes can be at individual, health system and population level. The consequences of poor retention at the level of the individual include decreased likelihood of receiving antiretroviral treatment, higher rates of antiretroviral treatment failure, increased HIV transmission risk behaviour, increased hospitalisation rates due to recurrence of opportunistic infections and death (Giordano et al., 2007; Mugavero et al., 2009). According to Assefa et al. (2011), patients who discontinue treatment are at high risk of developing resistance to antiretroviral drugs which subsequently leads to death. According to studies conducted in South Africa and Malawi, death is one of the consequences of poor retention among patients attending ART programs (Ahonkhai et al., 2012; Weigel et al., 2012).

Poor retention in care also puts the population at risk of HIV infection. There is a growing recognition that failure to attend HIV care within the recommended intervals results in increased viral burden at the individual, community and population levels, which is a potential driver of population-level risk for HIV infection and widespread transmission of drug-resistant virus (Horstmann et al., 2010; Mayer, 2011).

On the health system level, poor retention of patients in care can result in increased health care costs associated with increased hospitalization rates, emergency department use (Giordano et al., 2007). In addition, when patients fail treatment, the cost of treating these patients is high due to high costs of procuring second or third line ARV drugs. The cost increase is also associated with the cost of paying health workers during follow up visits.

The burden of caring for the patients also increases with congested hospital wards and outpatient department. A study conducted by Broughton, Nunez and Moreno (2014) suggest that retention of patients in care helps to contain health care costs by improving HIV-specific health outcomes and reducing emergency department visits and hospitalizations.

Mugavero, Norton, and Saag, (2011) also argue that attendance in HIV care with some degree of regularity is essential to individual living with HIV/AIDS and the general public. Furthermore, Tassle, Chamla and Souteyrand (2011) suggest that high retention rates are essential to maximize long-term health benefits of treatment and to ensure the sustainability of programs. In general, retention in care prevents new HIV infections, promotes good quality of life for those living with HIV infection and reduces mortality from AIDS-related illnesses. Therefore, retention of PLWH on ART program is critical.

## **2.5 FACTORS THAT AFFECT PATIENT RETENTION TO HIV TREATMENT**

Patient attrition from ART care is not exclusively an individual choice, but it is affected by other factors which interact to influence patient seeking behavior (Musheke et al., 2012). The factors affecting the retention of patients in ART programs can be categorized as: patient, social, health systems and economic related factors. This classification does not mean that the factors are isolated, as they are in some instances interrelated. For instance, according to Roura et al. (2009) health seeking behavior is shaped by the social environment. Mackian, Bedri and Lovel (2004) argue that health-seeking behavior is construed not as something that exclusively resides in the individual, but rather as a reflection of wider interactive situational processes.

### **2.5.1 Patient Factors**

Patient related factors comprise of personal characteristics such as perceived quality of life, side effects of the drugs interpretation of illness and wellness after registering some

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

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

### **2.5.2 Social Factors**

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

HIV and AIDS related stigma is a serious obstacle to long term retention. It can be at individual, household and community levels and it is characterized by rejection, denial and social distance (Musheke et al., 2012). Many people still associate HIV/AIDS with moral decadence and promiscuity, ultimately passing moral judgment on those infected. As a result, people living with HIV may face resentment, isolation and ridicule. Roura et al. (2009) argue that such attitudes and behavior do not only infringe on the rights of people living with HIV to respect and dignity but they also act as a strong disincentive for

them to make use of any existing services for fear of being given names. This eventually leads to discontinuation of ART. A study from Malawi shows that stigma leads to non-retention in up to 25% of patients on ART (McGuire et al., 2010). If universal access to treatment is to be achieved, effective strategies addressing stigma and discrimination must be developed. Stronger community involvement in the process of stigma analysis and development of responses is recommended.

### **2.5.3 Health System Factors**

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

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

Shortage of health personnel places considerable pressure on the scarce medical workforce (Decroo et al., 2013). This may result in long waiting times for patients at the facility. As a result, patients may be frustrated and discouraged from seeking care, leading to poor retention in care of the patients (Callaghan, Ford & Schneider, 2010).

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

#### **2.5.4 Economic Factors**

Although the governments of most African countries are making efforts towards scaling up ART programs to benefit people living with HIV, factors such as cost of drugs leading to stock outs are contributing to low retention rates in ART programs. Supply chain management problems leading to frequent stock outs of ARVs are hindering access to ART services (WHO, 2009). With the number of patients being initiated on treatment rapidly growing and a median price for first-line treatment of US\$143 per person per year in low-income countries, many health systems are finding it difficult to ensure that there are adequate drugs and other supplies (WHO, 2009). These countries are often undermined by weak procurement and supply management systems, resulting in frequent shortages of ARVs and other essential commodities. Evidence shows that 34% of 91 low- and middle-income countries have experienced at least one stock out of a required ARV drug (WHO, 2009).

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

Lack of formal education and poor health literacy about ART and HIV/AIDS can make patients not to understand about the effectiveness of medications. This may lead to challenges in adhering to treatment and poor retention in care (Tuller et al., 2010). At the initiation of ART, patients receive the most intensive counseling. However, once they are on treatment, counseling becomes less intensive unless there is a problem. Adherence counseling should be provided whenever patients visit the clinic for medication refills or any clinical appointments because this is the time when any other health problems can be identified (Reda & Biadgilign, 2012). However, if good retention rates in ART programs are to be attained, information, education, and counseling need to be emphasized.

## **2.6 STRATEGIES FOR IMPROVING PATIENT RETENTION IN CARE IN THE ART PROGRAM**

The global report on HIV highlights the urgent need to improve retention rates for people enrolled in ART programs (UNAIDS, 2014). Therefore, an effective tracking system to reduce the proportion of patients lost to follow-up is a critical requirement for ART programs. Evidence shows that programs that support people on ART in resource-limited settings with home visits or home-based care appear to have a significantly lower percentage of loss to follow-up than when ART is primarily facility-based (Decroo et al., 2013). In other words, there is something to be gained by supporting people on ART as close as possible to their homes.

The literature reveals several factors associated with improved retention of patients in care in ART programs. One way to overcome shortage of staff is task shifting which aims to obtain an optimal skill mix among the different professional categories within local health teams in order to increase the capacity to deliver ART services (Miller et al., 2010; Geng et al., 2010). Nurses can be used as ART prescribers (Miller et al., 2010) and lay workers, communities and people living with HIV/AIDS can also be engaged to deliver basic essential care functions to decrease the pressure on the scarce medical staff (Decroo et al., 2013). The authors argue that task shifting coupled with community participation



has the potential to address the workforce gap and make HIV care more available and closer to the communities.

Adherence or retention-related counseling is the duty of all health care providers involved in the delivery of ART in health facilities. Therefore, clinicians, nurses, pharmacy personnel and adherence counselors should all provide counseling services for adherence and retention (Assefa et al., 2011). The availability of social support services, such as peer support groups, use of the ‘buddy’ system of family members and adherence counselors have both been found to help patients adhere to ART. Therefore, integration of people living with HIV into the clinical team and using peer educators would help to improve retention of patients in care.

To reduce the waiting times of patient at ART clinics, Miller et al. (2010) recommended adopting extended clinic hours to serve those patients that are employed. Providing care after working hours or weekend clinic hours has been found to reduce clinic congestion and help retain patients in care. Community program models using expert clients to distribute ARV drugs in the community would also help to decongest the clinics and reduce waiting times (Mugisha et al., 2009).

Community tracking and tracing programs in which patients with missed visits are traced through phones or home visits using adherence support workers has also helped to retain patients in ART programs (Decroo et al., 2013). The use of electronic reminders such as text messages in Ethiopia (Assefa et al., 2011) and South Africa (Neethling et al., 2009) as well as fortnight phone calls from health care providers in Cameroon (Muko, Chingang & Yenwong, 2009) helped to avoid missed appointments and reduced lost to follow-up.

## **2.7 SUMMARY**

Retention in care remains a public health concern across African ART programs including Zambia, because only about 60% 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. These strategies



include: task shifting, extended clinic hours, community program models using expert clients to distribute ARVs in the community as well as community tracing programs. The following chapter describes the study setting and explains the research methodology used in the study.

## **CHAPTER 3 – RESEARCH METHODOLOGY**

### **3.1 INTRODUCTION**

This chapter describes the methodology used in the study. It outlines the study setting, study design, study population and sampling procedures used. It also describes the data collection procedure, which includes the research tools and the methods of data collection. It further describes the data analysis procedures. Finally the chapter addresses the issues of rigor, ethics, and the limitations of the methodology used.

### **3.2 DESCRIPTION OF THE STUDY SETTING**

The study was conducted in the Kabwe district of the central province in Zambia. Kabwe district is one of the six districts in Central province of Zambia. It shares borders with two large districts, Kapiri-Mposhi on the northern, eastern, and western parts; and the Chibombo district on the southern side. The Kabwe district is approximately 139km from the capital city Lusaka and covers a surface area of 1,577km squared (MoH, 2015). According to the Census of population and Housing of 2010, Kabwe has an estimated population of 210,979 inhabitants with a population density of 128.7 persons per square km. The population consists of 48.8% males and 51.2% females and the average annual

rate of population growth is estimated at 1.4% (CSO, 2012). According to the MoH data of 2014, the district population has increased to 217, 843 (MoH, 2015). Kabwe district is a transit town with a huge traffic of people moving through the Great North road to the Copperbelt and Northern part of Zambia from Lusaka and vice versa. The district is comprised of multilingual ethnic groups, with Bemba being the most widely spoken local language.

Economically, the Kabwe district has high (64%) poverty levels due to high unemployment rates brought about by the closure of factories and mines. Economic activities are mainly informal, though a few people are formally employed. Most people employed perform low-income jobs like taxi driving, bus conductors, house servants and general workers in the few available factories in Kabwe. Other occupations include employment in Government, parastatals and the private sector. The progressive industries offering employment includes Kabwe Industrial Fabrics Company, Zambia Railways Consortium, Dunavant Cotton, small scale mining at the old mine and the civil service including Kabwe municipality with the GDP per capita of 1.286 US\$ (CSO, 2011). The education levels in Kabwe district are very low. It is estimated that 40.8 % females and 59.2% males complete their primary education. This is mostly due to high school dropout.

### **3.2.1 The Health Status of Kabwe District**

The HIV incidence rate in Kabwe district has reduced from 18% in 2010 to 14% in 2014 and this has been attributed to the high number of individuals accessing ART and other preventive measures like male circumcision (MoH, 2015). The HIV prevalence in Kabwe district stands at 17.5% for 2014 (MoH, 2015). Kabwe district does not have a first level district hospital but refers complicated cases to Kabwe General Hospital. The district has only one facility (Ngungu Health Centre) which is a mini hospital and provides both out-patient and in-patient services with 45 bed capacity.

The district has a total of thirty six (36) health facilities that include 18 health centers run by the District Community Medical Office, four (4) by the Ministry of Defenses and Security, four (4) by the Ministry of Home Affairs and ten (10) by private organizations.

Out of these 36 health facilities, there are five (5) functioning health facilities in peri-urban areas, eleven (11) delivery centers and twelve (12) providing laboratory services. The district has eleven (11) health facilities that are providing ART services out of a total of 36 facilities while the provision of counseling and testing (CT) and Prevention of Mother to Child Transmission of HIV services (PMTCT) is being offered in all the health facilities.

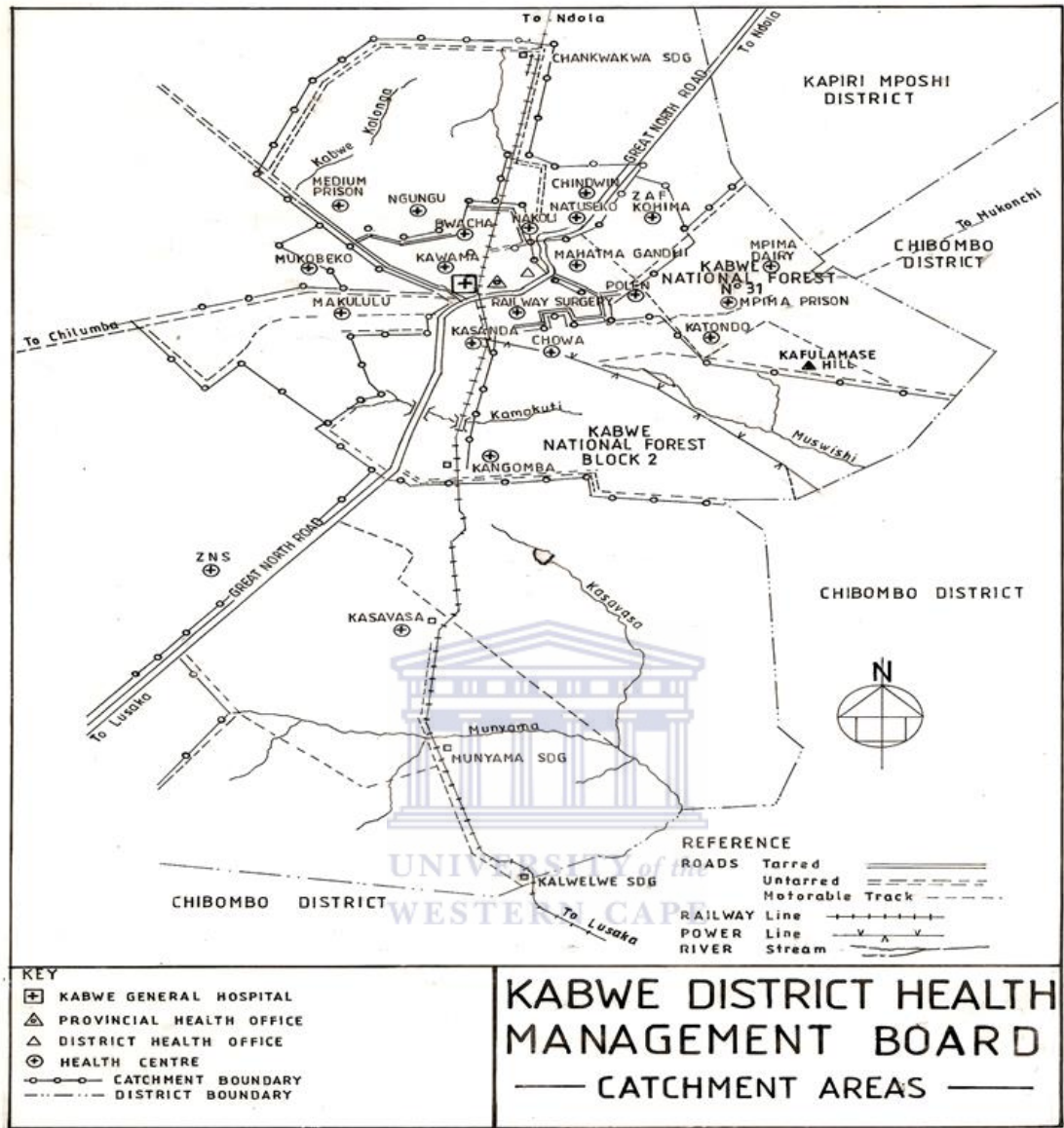
An estimated 28,562 patients have ever been enrolled on the ART program in Kabwe district with 18,215 patients currently accessing ART through the health facilities of Kabwe district as at 2013 (MoH, 2015). The ART program is being coordinated by a District Health Management Team. The district has one medical doctor based at the district health office supports ART clinics at different days. The three clinical officers who are based at the district health office also supports the ART clinics at different days. Kabwe district receives its drugs and laboratory supplies from the Medical Stores Limited, which is a government institution mandated to procure drugs and supplies on behalf of all Government institutions.

ART provision in Kabwe district is based on two treatment models (Test and Treat model and Treatment as prevention Model) (WHO, 2013). The clinical recommendations for ART guidelines include the following:

1. Starting lifelong triple combination ART (cART) in the following HIV-infected individuals:
  - All confirmed HIV-infected children and adolescents <15 years old regardless of CD4 count and/or World Health Organization Clinical Stage (WCS)
  - Adolescents  $\geq 15$  years old and adults with CD4 count  $\leq 500$  cells/mm<sup>3</sup> regardless of WCS
2. Starting lifelong triple combination ART regardless of CD4 count and WCS in:
  - Pregnant and breastfeeding women
  - HIV-infected sexual partners of pregnant & breastfeeding women
  - HIV-infected partners in sero discordant couples.

- Patients with active tuberculosis (TB) disease.
  - Patients with hepatitis B virus (HBV) co-infection with severe liver disease
  - Viral load testing as the preferred approach to monitoring cART and diagnosing treatment failure, in addition to immunological and clinical monitoring.
3. Community based HIV testing and counselling for early diagnosis of people infected with HIV and linking them to care and treatment.
4. Use of lifelong ART as a prevention strategy.
- For all pregnant and breastfeeding women to prevent mother to child transmission.
  - Reduce transmission of HIV to uninfected sexual partners.





**Figure 3.1: Map of Kabwe District Showing Health Facilities; Source: Kabwe District Action Plan 2015 – 2017**

### 3.2.2 Retention Rates for Three Health Facilities

This study was conducted at three (3) of the government supported ART clinics in Kabwe district. These included Makululu clinic, Ngungu clinic and Katondo clinic. All these clinics were purposively selected.

The retention rates at these three facilities are indicated in the table below. In the table below, the lost to follow up include the dead, relocations and probably self-referrals including those lost to follow up due to unknown cause. The attrition rate is high and should be a cause for great concern.

**Table 3.1: Retention rates for three health facilities**

<b>Name of facility</b>	<b>Patients ever on ART</b>	<b>Retained in Care</b>	<b>Patients lost to Follow-up</b>	<b>Retention percentage</b>
Katondo clinic	2024	1285	739	63%
Makululu clinic	2384	1559	825	65%
Ngungu clinic	3225	2204	1020	68%
<b>TOTAL AVERAGE RETENTION</b>				<b>65%</b>

### 3.3 STUDY DESIGN

This was an exploratory study using qualitative research methods. The study sought to gain a deeper understanding of the factors that affect the retention of patients on ART treatment. Qualitative methods can provide an understanding of health behavior in its every-day context and contribute answers to questions not easily addressed by other methods (Green & Britten, 1998). According to Joubert and Ehrlich (2012), people are a valuable source of information as they are able to verbalize their feelings and perceptions especially on issues that directly or indirectly affect them. Exploring sensitive issues is better articulated through interaction. Such an interaction offers an opportunity to capture the individual's point of view, examine their everyday life constraints and secure rich

descriptive data.

Lastly, the investigator used a qualitative exploratory study design because most studies examining factors associated with retention in care of patients on ART in Zambia have been conducted through the quantitative approach and little has been done to qualitatively explore the context within which the problem of retention in care occurs. For example, Musheke et al. (2012) used qualitative research methods to identify individual and contextual factors influencing patient attrition from antiretroviral therapy care in an urban community of Lusaka in Zambia. Therefore, a qualitative study was conducted because it could enrich our understanding of the complex nature of the retention problem for patients on the ART program in the Kabwe district.

### **3.4 STUDY POPULATION**

The primary study population comprised of 45 people living with HIV/AIDS, both male and female, aged between 18 and 49 years who are currently on antiretroviral treatment, have defaulted from the program, or have been declared lost to follow up after many attempts of follow up have been made. To this effect, the Zambian ART treatment guidelines recommend 60 days as a threshold for lost to follow up (MOH, 2014).

The second study population constituted nurses, doctors and adherence support workers working in an ART clinic, because they have the knowledge and experience about ART patients as well as have an understanding of the ART program. These were interviewed in three different focus group discussions, one at each clinic.

### **3.5 SAMPLING**

Using facility ART registers, electronic smart care system, pharmacy logbook and patient locator forms, a sample of 45 study participants (36 patients who are currently on ART and 9 those who have defaulted or have discontinued treatment) was selected using purposive sampling. Fifteen participants were selected from each ART site. Participants who were not able to come to the clinic were contacted and interviewed at their homes with the help of patient locator forms and the adherence support workers. Participants



were recruited through the health care professionals at each site.

According to Aluwihare-Samaranayake (2012), sampling strategies in qualitative research are designed to produce information-rich cases that yield in-depth understanding of all aspects of the phenomenon under investigation. Therefore, purposive sampling helped the researcher to identify information-rich cases to examine meanings, interpretations, processes and theory. The approach was also used for ART providers because of their knowledge and experience in providing ART services.

Participation in this study was voluntary. In a case where the potential participant refused to participate, another potential participant was selected using the same procedure. The selection and indeed the entire research undertaking ensured that there was no disruption of normal activities at the ART clinics as a result of this research.

### **3.6 DATA COLLECTION**

The data collection methods employed were individual interviews with patients using semi-structured (open-ended) and focus group discussions (FGDs) with health workers. Semi-structured interviews allowed the researcher to obtain more information about the reasons why HIV and AIDS patients discontinue ART. Interview schedules were also developed to guide the data collection process.

All interviews and the FGDs were conducted in Bemba, the local language which enabled the participants to express themselves explicitly and fluently. This ensured that the participants understood the questions and were in a position to express their views explicitly and accurately in their own language. The researcher conducted all the interviews and facilitated the FGDs herself.

The interviews and the FGDs were audio-taped with the participants' permission. In order to avoid using names and ensure anonymity of the study participants, they were given numbers. Each recording was labelled with a number for easy identification. The recorded interviews were transcribed and translated from Bemba to English by the researcher. An independent transcriber and translator was engaged to share a common understanding in the information collected. Part of the information was collected by



reviewing documents such as guidelines on antiretroviral treatment, smart care and registers.

### **3.6.1 Individual Interviews with Patients**

The purpose of a qualitative research interview was to obtain qualitative descriptions of the phenomenon with respect to interpretation of their meaning using a semi-structured guide (Mack et al., 2005; Rice & Ezzy, 1999). This guide had a series of open-ended questions. The qualitative research interview attempts to understand the subjects' point of view, to unfold the meaning of people's experiences using prompts which are helpful as a reminder to the researcher (Robson, 2011; Rice & Ezzy, 1999).

Individual interviews were conducted with 45 participants (15 from each of the three selected facilities). The participants were met individually. The researcher explained the purpose and objectives of the research to each participant, before their participation. The participants were eager to participate. Those who were able to read Bemba were given the participants information sheet to read and those who were not able to read, the information on the participant information sheet was explained to them. After making an informed decision to participate in the study, the participants were given the consent forms to sign. The interviews were conducted with the selected participants at the clinics when the ART clinics are being conducted. The interviews were conducted in a well-secured room arranged by the facility staff. This was done to avoid compromising confidentiality since the topic was sensitive. Participants who had defaulted or had discontinued ART were followed up in their homes with the help of adherence support workers and patient locator forms, which had patients' addresses. The interviews in most cases lasted about 30 minutes.

### **3.6.2 Focus Group Discussions with Health Care Workers**

FGDs are group discussions with participants who are similar to each other in a way important to the investigator to provide qualitative data in a focused discussion to help understand the topic of interest. The researcher held three focus group discussions with health care workers who are working at each of the three selected ART clinics. The

composition of each group was mixed with nurses, clinical officers and adherence support workers. A recommended number of 6 – 10 participants in a FGD was maintained. According to Mack et al. (2005) the focus group must be small enough for everyone to have an opportunity to share insights and yet large enough to provide diversity of perceptions.

At Makululu Health Centre, the sample had seven (7) health workers and at Katondo Health Centre, the focus group consisted of six (6) health workers while at Ngungu Health Centre, the focus group consisted of seven (7) health workers. The FGDs were held in ART rooms at Ngungu and Makululu health centers after all the patients had gone. At Katondo health center, it was held in the facility head's office. The FGDs were held at different days.

Before the FGDs, the researcher introduced herself to the participants who were later given the participants information sheet and FGD binding form to read through. After making an informed decision to participate in the study, the participants were given the consent forms to sign. The researcher also clarified the purpose of the study and what will be done with data. The FGDs were facilitated by the researcher who used the interview guide while a trained assistant took notes of non-verbal cues as the discussions were being audio taped.

### **3.7 DATA ANALYSIS**

After data collection, the audio tapes of the interviews were listened to repeatedly and transcribed into Bemba by an independent transcriber. The researcher then translated the transcripts from Bemba into English. The primary researcher re-read the transcripts independently and developed a coding frame for the analysis. The researcher used the five-stage framework approach (Taylor-Powell & Renner, 2003; Pope, Ziebland & May, 2000) to analyze the data which was informed by the aims and objectives of this study. The process involved: 1) reading through the transcription notes and listening to the recordings several times to be familiarized with the data, and obtain an overall impression; 2) identifying key issues and recurrent themes emanating from the data about participants' perceived factors affecting retention in care in ART programs. This was

sorted according to the questions that the researcher wanted the analysis to answer; 3) coding and organizing data into categories; 4) condensing and summarizing the contents of each of the coded groups; 5) interpreting data attaching meaning to the analysis.

### **3.8 RIGOR**

Rigor in qualitative research measures the credibility, dependability, transferability and conformability of data. It relates to whether the finding accurately reflect the real situation and are backed by evidence. It also refers to the extent to which the data collection strategies and instruments measure what they intend to measure.

Transferability refers to the degree to which findings can be applied in another context and settings or with other groups while conformability refers to the degree to which the results of the research can be confirmed by others especially external auditor who attempts to follow through the progression of events in research to try and understand how and why decisions were made (Krefting, 1991). Credibility refers to the confidence in the ‘truth’ of the findings while dependability shows that the findings are consistent and could be repeated (Lincoln and Cuba, 1985).

In this study, the researcher used semi-structured interview to collect data from the participants who are receiving ART treatment in three selected ART clinics and those who have defaulted treatment. Several strategies were employed in this study to ensure the trustworthiness of the findings.

The researcher ensured that participants are willing to participate in the study and are free to withdraw their participation from the study at any given time. According to Shelton (2004), the researcher must apply tactics to help ensure honesty in the informants. The participants were encouraged to be honest and truthful in their contributions. They were also assured that there was no correct or wrong answer.

Member checking was another strategy the researcher used to ensure credibility. Shelton

(2004) suggests that checks relating to accuracy of data may take place during the interview or at the end of an interview. In this study, the researcher ensured that participants' viewpoints were accurately translated into data. During interviews, the researcher summarized key points at the end of each interview to verify with the participants that the researcher's understanding and interpretation of the participant experiences, perceptions and opinions are correct and accurately represented (Shelton, 2004). After the interview, the recorded interviews were played back to the participants to overcome possible biases.

The researcher also examined previous research findings to ensure rigor of the study findings. Shelton (2004) puts emphasis on the importance of examining previous research findings to assess the degree to which the results of study are related to those of the past studies. In this study, the researcher read and used different literature to relate the findings of this study to existing body of knowledge.

Audit trail was also one of the strategies used in this study to ensure rigor. Shelton (2004) suggest that adequate trail should be left to enable the auditor to determine if the conclusions, interpretations, analysis and recommendations of the study can be traced to their sources and if they are supported by the inquiry. To achieve this, the researcher provided the participants with consent forms to sign. The consent forms explained the process and procedures of the research study.

Another strategy used to strengthen rigor and control bias was the use of different sources of information. Shelton (2004) suggests that method triangulation ensures comprehensiveness in the data collected. Source triangulation was employed in this study through the use of FGD and individual interviews. The use of FGD and individual interviews complimented each other and ensured rigor.

The researcher also acknowledged her personal beliefs of the research topic to avoid investigator bias due to personal perspectives. Shelton (2004) describe reflexivity as the extent to which the researcher admits his or her own position in research to ensure that the research findings are the result of the experiences and ideas of the participants rather

than those of the researcher himself or herself. The researcher was aware of her roles being a nurse by profession and as a researcher in the clinic.

I undertook the study in the region I have lived and worked for the past 13 years. I now work for John Hopkins Program for International Education in Gynecology and Obstetrics (JHPIEGO) under the Department of Defense program. JHPIEGO provides primary health care services such as reproductive health services, HIV/AIDS/TB/STI and capacity building for the health professional in Western, Southern, Central, Lusaka and Eastern provinces.

The researcher has some experience in the management of chronic conditions like HIV/AIDS. The researcher has also personal experience about the impact of HIV/AIDS at both family and community levels. During the field work, the researcher was identified by the gate keepers and participants as a researcher who had come to explore the factors affecting retention in care of HIV/AIDS patients on ART program in the Kabwe district community. To avoid suspicion, the researcher informed participants about her professional background. There was no evidence of respondents giving responses either to please the researchers or saying what they thought we wanted to hear. Most of the patients and health care professionals seemed to have enjoyed the discussions and spoke freely. While the researcher was keen to understand how the participants constructed their social lives, there was at no time any intimate and regular contacts established with the members of the groups studied.

### **3.9 ETHICS CONSIDERATIONS**

Ethics clearance was granted by the University of the Western Cape's Senate Research Committee and the Zambian ERES Converge ethics committee. Thereafter, the researcher applied for clearance by MoH Permanent Secretary through the Research Unit. The researcher also applied for permission to conduct and involve staffs and patients in the study in Kabwe District Health facilities. Authority to conduct research in Kabwe district was granted by both MoH and district Health office.

According to Cash et al. (2009), participants should be given adequate information concerning the research and its purpose to allow them to make an informed decision with regard to their participation in the study. The purpose and objectives of the study were explained to the participants before collecting information from them. The participants were informed that participation in the study was voluntary because participants should not be forced to participate in the study, but should create the opportunity and atmosphere for the participants to either refuse or agree to participate in the research. Only willing participants who understood the nature and purpose of the research, and agreed to participate in the study were enrolled as study participants. The participants were informed that they were free to withdraw from the study at any time and that they will not be penalized or lose the services that they were receiving at ART clinics.

The participants in the focus group discussion were asked to respect each other's opinion and were made to understand that all answers were correct. They were also informed of the importance of confidentiality within the group.

The participants were assured of the confidentiality of their information and anonymity of their identities. No names were used but during the FGDs, participants were assigned numbers to maintain confidentiality. Participants who were able to read and understand Bemba were provided with the participant information sheet to read. Those who were not able to read, the nature, purpose and objectives of the research, the expected benefits to the participants and the society, including any foreseeable risks of participating in the research were explained to them. This was done to allow the participants make an informed decision with regard to their participation in the study (Cash et al., 2009). The expected interview time was discussed with the participants. Permission was also sought to audiotape the interviews.

### **3.10 SUMMARY**

The goal of this chapter was to describe the methods that were applied in this study to identify the study populations. Individual interviews and FGDs were used to collect data putting into considerations the research ethics and how the trustworthiness of the study could be achieved. The collected data was analyzed thematically. The next chapter

explains the findings of this study under social, economic, patient and health system factors as the main themes.



## CHAPTER 4 – FINDINGS

### 4.1 CHARACTERISTICS OF STUDY PARTICIPANTS

The characteristics of study participants are presented in table 4.1 below. A total of 45 ART patients were interviewed as participants; out of which, 25 participants were female and 20 were male.

Most of the participants (21) ranged between 25 – 34 years old and 14 participants were between 35 – 44 years old. Furthermore, three participants were between 18 – 24 years and seven participants were 45 years old and above.

The majority of the participants (23) were married; with a further 10 participants widowed. Eight participants were single and 4 participants were either divorced or on separation.

More than half of the participants (29) had primary school as highest level of education attained while 13 participants had attained secondary school education and three had not received any formal education.

The majority of the participants (32) were self-employed and were selling merchandise or cleaning cars. Only 2 participants had formal employment; while 7 participants reported being unemployed and 4 participants reporting that they were dependents being supported financially by parents or other relations.



**Table 4.1: Characteristics of Participants**

	Frequency (N = 45)
<b><u>Sex</u></b>	
Female	25
Male	20
<b><u>Age (in Years)</u></b>	
18 – 24	3
25 – 34	21
35 – 44	14
45 and above	7
<b><u>Marital status</u></b>	
Single	8
Married	23
Divorced/Separated	4
Partner died	10
<b><u>Level of Education</u></b>	
None	3
Primary school	29
Secondary school	13
Tertiary	0
<b><u>Source of Livelihood</u></b>	
Formal employment	2
Self-employed	32
Unemployed	7
Dependents	4

#### 4.2 DESCRIPTION OF HEALTH WORKER PARTICIPANTS

Additionally, a total of 20 health workers participated in the focus group discussions as participants. Three focus group discussions were held; one at each site. Nine (9) nurses, 5 clinical officers and 6 adherence workers participated in the study as FGD participants as shown in the table 4.2 below.

**Table 4.2: Characteristics of health workers in three FGDs**

<b>Category of Health workers</b>	<b>Katondo Clinic</b>	<b>Ngungu Clinic</b>	<b>Makululu Clinic</b>	<b>Total</b>
Nurses	4	2	3	9
Clinical officers	1	3	1	5
Adherence workers	1	2	3	6
<b>TOTAL</b>	<b>6</b>	<b>7</b>	<b>7</b>	<b>20</b>

From the table 4.2 above, nine (9) nurses, 5 clinical officers and 6 adherence workers participated in the study as FGD participants.

### 4.3 SUMMARY OF THEMES AND SUB-THEMES

The main factors reported as affecting retention of patients on ART program in Kabwe district are outlined below in table 4.3 under themes with their sub-themes.

**Table 4.3: Factors Affecting Retention in Care**

	<b>THEMES</b>	<b>SUB-THEMES</b>
1	Patient Factors	Side effects
		Weight increase as a sign of good health
		Alcohol use
2	Social Factors	Stigma and non-disclosure of HIV status
		Herbal remedies
		Faith healing
3	Health System Factors	Staff shortages
		Long waiting times
		Stock out of ARV drugs
		High patient load
		Inadequate space for ART clinic
		Travel distance to ART centers and transportation cost
4	Economic Factors	Food shortage
		Traveling on duty

## 4.4 PATIENT FACTORS

Patient factors include personal characteristics, knowledge and attitudes towards treatment, weight gain, interpretation of illness and wellness. Two patient factors were identified.

- Weight increase as a sign of good health
- Side effects of ARV drugs

### 4.4.1 Weight increase as a sign of good health

Many patients default ART treatment after they notice an increase in weight and start looking healthy. The majority of participants revealed that some patients stop taking their medication because they were feeling better and physically fit. Some participants reported cessation of body pains as a sign of healing.

*'Some patients stop taking ARV medications when they see that they increase in weight and look healthy. They feel they can do away without the drugs especially when their CD4 count is high. This affects adherence and later impacts on long term retention'* – health care worker.

*'Some patients feel they are healed when they increase weight and start feeling better. There is this patient in my neighborhood. He stopped taking his ARV medication after becoming well. He said there was no need for him to continue taking the ARV drugs'* – 37 year old woman.

*'I just hear that when people take ARVs for a long time they become HIV negative. They think they are healed. So as a result they stop taking ARVs'* -30 year old man.

*'To some when they get better and increase weight they stop their medication. My cousin stopped when she got better and increased her body weight with no body*

*pains* – 28 year old widow

#### **4.4.2 Side effects**

Some participants mentioned side effects as one of the reasons why some patients discontinue ART. Some of the side effects reported were nausea, vomiting, dizziness and breast enlargement in male patients. These may affect patient seeking behavior and may lead to attrition from ART care because being male patients, breasts interfere with their engagement in livelihood activities.

*‘Observations made were that a few patients especially men may stop their ARV medications because of side effects like developing breasts (gynaecomastia). Patients feel they have something else on their bodies and so they end up stopping their medication. Other patients stop their medications because of nausea, vomiting and dizziness. Such are the patients who discourage the rest of the community to stop ARV drugs’ – Health care worker.*

#### **4.5 SOCIAL FACTORS**

Social factors influence the health of people and communities. They affect patient lifestyle by causing stress, social isolation and fear of rejection. When a patient’s emotions, opinions, or behaviours are affected by others, adherence to medication and long term retention is affected. The social factors may include experiences, interpersonal relationships with marital partners, family members that in turn affect individual health seeking behavior and actions. The majority of participants reported social factors to affect adherence and long term retention. Four social factors were identified as follows:

- Stigma and non-disclosure of HIV status
- Faith healing
- Herbal remedies.

- Alcohol use

#### **4.5.1 Stigma and non-disclosure of HIV status**

HIV related stigma was reported as one of the reasons why some patients discontinued ARV treatment or missed treatment dosage. Some patients do not want to disclose their HIV status either to their marital partners or other social network members for fear of domestic violence, partner abandonment or rejection by the community. As a result, patients opt to stop treatment which in itself affect adherence and long term retention.

*‘Couples do not want to disclose their status to each other. You find that the wife is on ARVs without the husband knowing or the husband is on treatment without the wife knowing. Sometimes you find that the husband is taking drugs from the office without the partner being aware’* – Health care worker.

*‘Some patients hide from their relatives. Some patients who look healthy and want to marry or get married, they hide and give up on treatment so that their partners don’t get suspicious of their HIV status since they may lead to end of the relationship. I have a sister from my mother’s sister. She is now dead. She got married and hide her HIV status from her husband and stopped taking her ARV drugs’* - 34 years old woman

Additionally, health care workers confirmed that stigma was still high at individual and community levels.

*‘Stigma is still very high among the well to do people and those in business. 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.

#### **4.5.2 Faith Healing**

Religious beliefs and practices also lead to patient attrition from ART care. The majority of participants reported how some church pastors in their communities who conduct healing prayers sessions are persuading patients to discontinue ART treatment because they are healed.

*'There are some pastors who tell patients to stop taking their ARV medication if they pray for them. They say that they are healed'* - 45 year old widower.

*Some people go to some pastors who pray for them and tell them to stop taking their ARV drugs that they are healed. I have seen these people who discontinue treatment. One even died after stopping taking these drugs. He was my neighbor'* – 42 year old widow.

*'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. Sometimes when they feel sick that's when they reveal that I had stopped because I was told to stop because I was healed'* – Health care worker.

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### **4.5.3 Herbal Remedies**

Use of herbal remedies to treat HIV related illnesses was reported by the majority of the participants as a cause for discontinuation from ART program. Some patients were being told that herbal remedies can cure HIV and AIDS and some were told that they boost the body immunity. These influence the health seeking behavior of patients leading to discontinuation of ART treatment. 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.

*'My neighbor used to drink these herbal remedies called Moringa from traditional healers because he was told it heals all diseases including HIV and AIDS. Unfortunately he died'* – 32 year old woman.

*'HIV patients use Aloe Vera medicines concurrently with ART as immune boosters. Overtime, we have observed that these patients stop taking their ARV drugs and concentrate on traditional medicines and eventually discontinue ART treatment through death'* – Health care worker

*'Some patients especially those from rural settings find this traditional medicines easily accessible and they have more confidence in tradition healers. Whatever they say is right. That component is also affecting patients' adherence to treatment and retention in care* – Health care worker.

#### **4.5.4 Alcohol use**

Excessive beer drinking was reported to be a factor affecting patient retention in care. Some participants reported to have resorted to excessive beer drinking after registering great improvement in their health. This beer drinking leads to interruption of medication which later impacts on adherence and long term retention in care.

*'It have been now close to one year 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'* – 32 years old woman.

### **4.6 HEALTH SYSTEM FACTORS**

Health system factors relate to the way health services are organized and delivered. They may include logistics (materials to use), waiting time, shortage of staff and high patient load. The majority of the participants expressed concern about shortage of staffs, long waiting times at the clinic, shortage of third line ARVs, high patient load and inadequate space for ART provision.

#### **4.6.1 Staff shortage**



The majority of the participants reported shortage of trained clinic staffs to be a factor affecting retention in care of patients on ART treatment. They claimed to have one to two qualified staff during the ART clinic day to attend to a long queue of patients. Because of this, patients get frustrated and tired of waiting to be seen.

*'There are few health workers to attend to patients at ART centers. In most instances only one clinical officer or one nurse on full ART day working with two adherence support workers against a crowd of patients. Some patients get tired of waiting and go back home without being seen'* – 36 year old woman.

*'So there is only one person remaining at ART clinic to see patients. This clinical officer is overwhelmed with work and two days a week is too much for this person. So there is a lot of compromise. If you saw today the queue that was there. He had to review the in-patients first and then outpatients. It's too much'* – Health care worker

*'When you are alone on duty, it becomes difficult to identify early those patients who miss the day's appointment or default because you just work fast to try and clear the long queue. This contributes to poor retention of patients in this program'* – Health care worker.

*'There is still a very acute shortage of trained health workers in this district to offer ART treatment to PLHIV. The patient provider ratio is still very high'* – Health care worker.

It was also reported that several patients discontinue treatment because of long waiting times at the ART clinics. Participants complained about long waiting times which made them more likely to stop coming to the clinic to collect their drugs. Most of the participants reported long waiting time of 4 – 6 hours at the clinics before going back home.

*'The health workers are few. Sometimes there can be only one. The rest could be these volunteers. That is the reason why we even spend more time here'* - 37 year old widow.

*We take a long time here. Sometimes I spend about 4 hours and sometimes 5 hours depending on the time they start the clinic. This is frustrating. You can even stop coming to this clinic to collect ARV drugs’ – 37 year old widow.*

Some participants reported high patient load at ART centers to have led to long waiting times and at some ART centers it has contributed to high defaulter rates.

*‘Actually we have a lot of patients at these clinics in relation to the health care workers. When we look at the trained adherence support counselors they are not even enough to cater for all the patients’ - Health care worker.*



**Figure 4.1: Patients waiting to be seen by clinician at one of the clinics in Kabwe district.**

#### **4.6.2 Stock out of ARVs**

The majority of participants reported ART clinics to have been running low on the ARV

stocks. This had led to patient being given ARV supplies sparingly. Some participants reported receiving one month supply of ARV drugs when a three months' supply had been prescribed while other participants reported frequent visits to the ART centers to be tiring especially when one does not have transport money. One participant reported a stock out of third line drugs which are mostly found at referral hospitals and patients had to travel to access treatment.

*'If they say there is a shortage of ARV drugs, they write medication for three months but they will give you for one month then tell you to come and collect for remaining months. When you come you just go straight to the pharmacy. But this sometimes makes you tired especially where you have transport money' – 28 year old man.*

*'We had a stock out sometime last year but all of this year we never had a stock out. We had a lot of challenges for third line ARV drugs. We have some patients who are on third line treatment. Those on third line are not accessing their drugs here despite being under this clinic. Then they go to Lusaka to access treatment. Because of this they may not have transport to go to Lusaka for drugs. For example we had to make contributions for transport for one to go to Lusaka' – Health care worker.*

#### **4.6.3 Inadequate space for ART clinic**

At one clinic health worker participants reported limited space for 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 the office for sister in charge which do not provide waiting area for patients. In this case confidentiality (privacy) during ART clinic is compromised because of overcrowding of patients.

*'We don't have enough space at this clinic for ART patients. Instead, we use any room not in operation during the ART day, either the office for the sister in*

*charge or the Male circumcision room. You can just see how this passage is congested. Because of this, even space for individual counseling has become a challenge as it leads to loss of patients in ART program because confidentiality is compromised’ – Health care worker.*

*‘Some patients tend to shun ART services where there is no confidentiality. We have a lot of patients who are lost to follow up because of the same confidentiality due to lack of space for ART clinic’ – Health care worker.*

#### **4.6.4 Travel distance and cost of transportation**

Although ART treatment sites do not charge for HIV related services, travel distance and additional costs incurred traveling to ART centers may contribute to non-retention in care of patients on ART program especially more for patients who cannot afford it. Some participants reported travel distance to ART centers as a barrier to accessing treatment and some mentioned lack of money as a reason for defaulting.

*‘Distance from home to the clinic is very long. I take one hour walking to this clinic when I am fast. I can even take one hour 30 minutes if am not fast. Sometimes, if am not feeling well, I cannot walk this distance and if I don’t have someone to come and collect the drugs for me, I miss the appointment date and come later when I feel better’ – 42 year old widow.*

*‘Patients coming from very far places may take them at least two to three hours to reach the clinic. Sometimes they do not come to collect their drugs due to lack of transport money’ – Health care worker.*

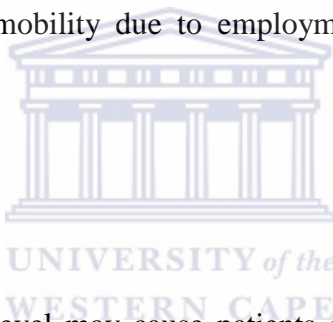
*‘Some patients who stay from distant places struggle to come to the clinic because of transport costs. Sometimes they would even resist to starting treatment or when they start they will pretend they will come back to the clinic because of distance’ - Health care worker.*

*‘The other reason is about distance. Some places become impassable during especially rainy season and it’s not easy for them to access ARVs. You find in some areas bridges are swept away and this will cause some patients to default*

*treatment. So, they can't find their way to the clinic' - Health care worker.*

## **4.7 ECONOMIC FACTORS**

The economic factors are factors due to the economic situation of a country. These can include poverty, shortage of food, lack of transport, costs of drugs, unemployment etc. Some participants reported shortage of food as a barrier to accessing treatment while some participants mentioned mobility due to employment as a reason for defaulting treatment.



### **4.7.1 Food shortage**

Food insecurity at household level may cause patients on ART treatment to stop their medication. Some participants reported shortage of food in the household as a reason to default treatment which may impact on adherence and long term retention.

*'People who come from the poor settings where they have shortage of food believe that they need to eat before they take ARV drugs. They will even tell you that I stopped because there was no one to buy food for me' – Health care worker.*

*'But some patients stop treatment because they don't have food in their households. My neighbor stopped taking her ARV drugs because of shortage of food. She was afraid to take the ARV drugs on an empty stomach' - 25 year old woman.*

### **4.7.2 Mobility due to employment**

According to the findings from FGDs, patients who travel whilst on duty tend to default ART treatment and this contributes to non-adherence and poor retention. Two participants mentioned truck drivers who had defaulted treatment for months and then reappear again for treatment. This is what they had to say:

*‘The other reason is I have seen a lot of truck drivers. They tend to travel when given a contract. Then you find for months they will disappear. When they appear and you ask them why they disappeared, they say they went for work’* – Health care worker.

*‘Some patients miss treatment appointments when they travel to go and work in another town. I can attest to this. My neighbor is always traveling and when he comes back, he mentions not having taken his ARV drugs for a long time’* - Health care worker.


#### **4.8 SUMMARY**

The study results indicated that patient, social, health systems and economic concerns affect patient retention in care particularly staff shortage, 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 addition, 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.



## CHAPTER 5 – DISCUSSION

### 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 Kabwe district. As stated earlier in Chapter three, the objectives of the study were to: 1) explore the economic factors that influence retention in care of patients on ART program in the Kabwe district, 2) explore the structural factors that influence retention in care of patients on ART program in the Kabwe district and 3) explore the social factors that influence retention in care of patients on ART program in the Kabwe 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, social, health system and economic related factors. The study also demonstrates how individuals adjust their behavior to their immediate social environment which also affect their health seeking behavior. According to Roura et al. (2009), the processes through which other people's behaviors, advice and beliefs determine health behavior emerges as a main pathway for individual decision making and reflects localized norms and levels of support within individual's social networks. Roura et al. (2009) also argued that the strength of social influence could severely undermine capacity to follow through an

intention to remain on treatment leading to dropping out from the treatment program.

## **5.2 PATIENT – RELATED FACTORS**

Patient 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 Mugisha et al. (2009); Roura et al. (2009) and Musheke et al. (2012). Discontinuation of ART treatment due to gynaecomastia and perception of good health indicates that patients are not properly educated on the issues of HIV/AIDS and ART. It also shows that the expert opinions of the providers are not trusted enough to enable patients remain in care. Roura et al. (2009) argue that individual seeking behavior is influenced by factors in the immediate environment. Therefore, patients need to be encouraged to remain in care despite drug side effects. Intensive counseling should be employed in order to increase ART knowledge levels.

## **5.3 SOCIAL 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. 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. (2012) reported feeling better, use of herbal remedies and faith healing as factors contributing to poor retention. A similar study conducted in Uganda by Mugisha et al. 2009 also reported stigma and traditional healers as greatest impediment to ART access, adherence and long term retention in care which is at individual, household and community levels. 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 challenged, patients on ART treatment are unlikely



to access the life drugs and hence compromise long term retention in care.

#### **5.4 HEALTH SYSTEM 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 shortcomings of ART delivery, which are partly due to resource constraints. Almost all the patients interviewed and health care workers reported long waiting hours at health facilities due to high patient loads, staff shortages, shortages of third line ARV drugs. Similar to findings from the previous studies, Alamo et al. (2013), Watt et al. (2009) and Miller et al. (2010) respectively reported long waiting hours at health facilities due to high patient loads which affected patient access to treatment. Long waiting hours is among the key drivers of attrition for patients on ART. The study conducted in by Miller et al. (2010) recommended adopting extended clinic hours providing care after working hours or weekend clinic hours, especially for those patients that are employed. Weekend clinics have been found to reduce clinic congestion and help retain patients in care. The study, therefore suggests that clinic days be increased from two days a week to five week days to try and reduce congestion and help retain patients in care and if possible employ weekend clinics.

On the other hand, despite task shifting in Kabwe district, the high patient load at health facilities surpass and defeat the efforts of health care workers to include adherence support workers. To this effect, the study suggest that community-capacity building through ART community models using PLHIV to deliver ART to stable patients on ART in their communities would help to decongest the ART clinics and help retain patients in care.

Similarly, in a qualitative study conducted in Sub Saharan Africa by Decroo et al. (2013), reported that task shifting coupled with community participation have the potential to address the workforce gap and make effective HIV care more widely available and closer to the communities thereby overcoming barriers to retention and decongest health services.

Another study conducted in Central Mozambique to examine the relationship of patient volume, human resource levels and patient characteristics with attrition from HIV treatment programs concluded that patients attending clinics with higher staff burden had a higher risk of patient attrition (Lambdin et al., 2011). Therefore, this study also suggest that more people who are trained as nurses or clinical officers be employed by the Ministry of Health. Hence, more nurses and clinical officers can be trained in the provision of ART services so that patients on ART can be seen throughout the week. This will help to reduce congestion and help to retain more patients in ART care.

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. Third line treatment can only be accessed in Lusaka which is 139 km away from Kabwe. This study shows that distance to ART clinic is a barrier to both ARV adherence and access to care which may affect long term retention in care for patients in ART program.

Similarly, a study conducted in Zambia by Musheke et al. (2012) also reported distance to ART centers as a barrier to patient retention in care. 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 et al., 2010) 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.

## **5.5 ECONOMIC FACTORS**

The economic factors such as level of knowledge, employment status, shortage of ARV drugs and lack of food may influence patient retention in care. The study found that all

the patients interviewed had lower levels of education. None of them had reached the college or university level. Lower educational level can influence adherence and can have some effects on patients' health seeking behavior.

The livelihood is another thing of concern. Only two patients interviewed had formal employment but the rest had informal type of employment or are not working. The living conditions and monitoring survey of 2006 – 2010 confirm that 64% of Zambia's population falls below the national poverty line of US\$1.08 per day and 90% of the labor force is in informal sector employment (CSO, 2011). Even where People Living with HIV are motivated to continue accessing treatment, the health seeking behavior is undermined by the fragile livelihoods. A study report from Weiser et al. 2010 showed some concerns about the widespread poverty and food insecurity at household level as this may impact on long term retention on ART treatment. While food insecurity remains an important public health concern and a salient issue among the disadvantaged population, strategies to support such a population should be employed in order to improve long term retention into care of patients on ART program.

Stock out of drugs was also reported by health care workers. The WHO (2010) reported weak procurement and supply management systems in low-income countries which result in frequent shortages of ARVs and other essential commodities. Similarly, many health systems are finding it difficult to ensure that there are adequate drugs and other supplies especially with the increasing number of patients initiating treatment (WHO, 2009). Therefore, there is need for the district to strengthen its ARV supply chain management system to meet the needs of the growing number of patients on ART program and achieve high retention rates.

Although health care workers interviewed in this study during the FGD reported intensive counseling of patients before and after ART initiation, the patients knowledge and beliefs related to HIV and ART treatment clearly showed that inadequate information is being given and that myths and misconceptions from the community are not dispelled and corrected. A study conducted by Tuller et al. (2010) reported that lack of education and poor knowledge about ART and the HIV/AIDS can also lead to an inadequate understanding about the effectiveness of medications resulting to reduced adherence to treatment and poor

retention of patients in care. The patient seeking behavior can also be determined by the information that a given health care system provides.

It is therefore the duty of all health care workers including adherence counselors to correct all myths and misconceptions coming from the communities and hence, improve retention of patients in care, taking into account the educational levels of the individual patient.

### **5.6 LIMITATIONS OF THE STUDY**

Despite 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 as well as the Zambian approval processes affected the study by disturbing the scheduled dates for the mini-thesis.



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## **CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS**

### **6.1 CONCLUSIONS**

Since the inception of ART, ART programs in Africa have retained about 64% of their patients at the end of three years on ART. The average retention rates in Kabwe district is about 65% and 35% are considered as lost to follow-up mainly due to social, economic and structural factors. The findings of this study suggest that low retention rates are an indicator of major weaknesses in the support system around the patient. The program resources could also be scarce. 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**

Retention in care is still a challenge in Zambia and requires team work to improve it for the larger population. Therefore, the health care providers, the district health team and policy makers are all important and active participants. In order to improve retention rates, key strategic and programmatic areas need to be addressed.

#### **6.2.1 Recommendations regarding patient factors**

Patient factors included side effects, excessive beer drinking, feeling better. Many 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, heavy drinking should be discouraged by substance abuse counselors because it can make Efaviraz side effects worse in particular dizziness. It can also make hepatitis or other liver complications progress more quickly. In addition, patients should be provided with support systems that includes family, friends and other patients that

may act as role models. With regards to the development of breasts in males, patients involved need to be reassured with continuous counseling.

### **6.2.2 Recommendations regarding social factors**

Stigma and non-disclosure of HIV status was perceived to be a hindrance to achieving good adherence and retention in care of patients on ART program. The study therefore suggest that health care providers including adherence support workers should take an active role in the fight against stigma. This should be done by developing a multi-sectorial approach where by all stakeholders are involved in developing a policy against stigma. The health care providers have also the obligation to inform the patients fully and help them understand HIV by dispelling myths and misconceptions coming from the communities. Strategies that can encourage patients to improve on disclosure of HIV status should be developed. Furthermore, ART services should be incorporated into the out-patients services rather than ART services operating as a stand-alone program.

### **6.2.3 Recommendations regarding health system factors**

Travel distance could be a geographical factor that could have an effect on long term retention of patients on ART program. To reduce on the distance that patients have to travel to health centers, the government through Ministry of Health (MoH) and Ministry of Community Development Mother and Child (MCDMCH) should be able to consider accreditation of more health facilities to provide ART and reduce the workload on the existing ART sites. 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.

Shortage of staff was a factor affecting retention at ART centers. The MoH and MCDMCH should consider training and placement of nurses and clinical officers to address staff shortages. The government through MoH and MCDMCH should help to address human resource problems such as low pay and retention. More nurses and

clinical officers 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.

Despite task shifting in Kabwe district, the high patient load at health facilities surpass and defeat the efforts of health care workers to include adherence support workers. To this effect, the study recommends ART community models using PLHIV to deliver ARVs to stable patients in their communities would help to decongest the ART clinics and help retain patients in care.

The district health management team should be able to form mobile training and mentorship teams so that all ART sites receive regular physician support for HIV and AIDS care provision. If possible the same team should act as the mobile ART team to support clinics where there are no staffs. The district should also be able to establish regular audit meetings for ART Clinic managers to share challenges, as well as promising practices on a monthly or quarterly basis. This should also serve as a forum for the district information managers to review ART databases and offer the necessary technical support.

Another impediment to patient retention was long waiting hours and high patient loads at ART centers. Heavy patient loads may lead to higher stress levels causing burnout among health care workers. To help reduce the burnout, managers can provisionally reduce the workload by providing employees with a flexible schedule and plan vacations. The Ministry of Health Zambia should also try to improve retention for health care professions by improving working conditions and incentives. This will also help to bring back health care professionals who have left the country for greener pastures. There is



also need to open more schools to train health care workers. Adopting extended clinic days to cover all the days of the week including week end clinics will help to reduce congestion at these ART sites and help to reduce burnout for clinic staffs.

A significant proportion of patients on ART are lost to follow up. Strong Community follow-up and patient support systems should be a precondition for all ART Programs in Kabwe district. It is important to understand that HIV is both a social and health problem. Therefore, there is need to engage a wider range of partners such as community based and faith based organizations and communities themselves in particular PLWH to improve patient tracking and follow up and hence, retain them in care. Experienced clients on ART (Expert clients) should be used. The district should also be able to hold regular meetings for ART clinic managers involving community local organizations to share challenges and discuss patients who are lost to follow up. This could also serve as a forum for the district health information manager to review the health center level data and offer necessary technical support.

The policy makers should review empirical research focusing on interventions to improve retention in care of patients on ART program and come up with interventions that are specific to the Zambian populations.

#### **6.2.4 Recommendations regarding economic factors**

The study revealed that patients who are started on ART treatment come to discontinue treatment due to shortage of ARV drugs, food shortages and cost of transportation to ART centers. With regard to lack of money for transportation, patients need to be continually encouraged to take treatment at their nearest treatment center. With regard to food insecurity, patients also need to be encouraged to be self-reliant by establishing projects such as gardening in their households to alleviate poverty. This should be facilitated by nutritionists at each clinic in partnership with the food and nutrition commission With regard to stock out of ARV drugs, there is need for the MoH and MCDMCH and in particular the district health office to strengthen the ARV drug stocks

and logistics supply chain management in order to avert stock outs caused by the inefficiencies in the supply chain system.

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UNIVERSITY of the  
WESTERN CAPE

## APPENDICES

### APPENDIX 1: SCHOOL APPROVAL

OFFICE OF THE DEAN  
DEPARTMENT OF RESEARCH DEVELOPMENT

18 December 2014

#### To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:

Ms JC Mwale (School of Public Health)

Research Project: Factors affecting retention in care of patients on anti-retroviral treatment in the Kabwe District, Zambia.

Registration no: 14/10/56

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

*Ms Patricia Josias*

*Research Ethics Committee Officer*

*University of the Western Cape*



Private Bag X17, Bellville 7535, South Africa  
T: +27 21 959 2988/2948 . F: +27 21 959 3170  
E: [pjosias@uwc.ac.za](mailto:pjosias@uwc.ac.za) [www.uwc.ac.za](http://www.uwc.ac.za)

A place of quality,  
a place to grow, from hope  
to action through knowledge



**APPENDIX 2: ERES CONVERGE APPROVAL**

**33 Joseph Mwilwa Road  
Rhodes Park, Lusaka  
Tel: +260 955 155 633  
+260 955 155 634  
Cell: +260 966 765 503  
Email: eresconverge@yahoo.co.uk**

**I.R.B. No. 00005948  
F.W.A. No. 00011697**

16<sup>th</sup> March, 2015

**Ref. No. 2015-Feb-005**

The Principal Investigator  
Ms. Joyce Chali  
285 Nyumba Yanga  
Off Godfery Chitalu Rd  
LUSAKA.

Dear Ms. Chali,

**RE: FACTORS AFFECTING RETENTION IN CARE OF PARTICIPANTS ON ANTIRETROVIRAL TREATMENT IN THE KABWE DISTRICT ZAMBIA.**



Reference is made to your corrections dated 13<sup>th</sup> March, 2015. The IRB resolved to approve this study and your participation as principal investigator for a period of one year.

Review Type	Ordinary	Approval No. <b>2015-Feb-005</b>
Approval and Expiry Date	Approval Date: 16 <sup>th</sup> March, 2015	Expiry Date: 15 <sup>th</sup> March, 2016
Protocol Version and Date	Version-Nil	15 <sup>th</sup> March, 2016
Information Sheet, Consent Forms and Dates	• English.	15 <sup>th</sup> March, 2016
Consent form ID and Date	Version-Nil	15 <sup>th</sup> March, 2016
Recruitment Materials	Nil	15 <sup>th</sup> March, 2016
Other Study Documents	Interview and Focus Group Discussion Guides.	15 <sup>th</sup> March, 2016
Number of participants approved for study	45	15 <sup>th</sup> March, 2016

Specific conditions will apply to this approval. As Principal Investigator it is your responsibility to ensure that the contents of this letter are adhered to. If these are not adhered to, the approval may be suspended. Should the study be suspended, study sponsors and other regulatory authorities will be informed.

### **Conditions of Approval**

- No participant may be involved in any study procedure prior to the study approval or after the expiration date.
- All unanticipated or Serious Adverse Events (SAEs) must be reported to the IRB within 5 days.
- All protocol modifications must be IRB approved prior to implementation unless they are intended to reduce risk (but must still be reported for approval). Modifications will include any change of investigator/s or site address.
- All protocol deviations must be reported to the IRB within 5 working days.
- All recruitment materials must be approved by the IRB prior to being used.
- Principal investigators are responsible for initiating Continuing Review proceedings. Documents must be received by the IRB at least 30 days before the expiry date. This is for the purpose of facilitating the review process. Any documents received less than 30 days before expiry will be labelled "late submissions" and will incur a penalty.
- Every 6 (six) months a progress report form supplied by ERES IRB must be filled in and submitted to us.
- ERES Converge IRB does not "stamp" approval letters, consent forms or study documents unless requested for in writing. This is because the approval letter clearly indicates the documents approved by the IRB as well as other elements and conditions of approval.

Should you have any questions regarding anything indicated in this letter, please do not hesitate to get in touch with us at the above indicated address.

On behalf of ERES Converge IRB, we would like to wish you all the success as you carry out your study.

Yours faithfully,  
**ERES CONVERGE IRB**



Dr. E. Munalula-Nkandu  
BSc (Hons), MSc, MA Bioethics, PgD R/Ethics, PhD  
**CHAIRPERSON**



All Correspondence should be addressed to the  
Permanent Secretary  
Telephone: +260 211 253040/5  
Fax: +260 211 253344



REPUBLIC OF ZAMBIA  
MINISTRY OF HEALTH

In reply please quote:

MH/101/17/6.....

NDEKE HOUSE  
P. O. BOX 30205  
LUSAKA

9<sup>th</sup> April, 2015

Joyce Chali Mwale  
285 Nyumba Yanga  
Off Godfrey Chitalu Rd  
LUSAKA

Dear Mrs. Joyce Chali Mwale,

**Re: Request for Authority to Conduct Research**

The Ministry of Health is in receipt of your request for authority to conduct research titled **“Factors Affecting Retention in Care of Participants on Antiretroviral Treatment in the Kabwe District Zambia.”** I wish to inform you that following submission of your request to my Ministry, our review of the same and in view of the ethical clearance, my Ministry has granted you authority to carry out the above mentioned exercise on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to MoH quarterly from the date of commencement of the study;
3. The final study report is cleared by the MoH before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the MoH, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, and all key respondents.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'D. M. Chikamata'.

Dr. D. M. Chikamata  
Permanent Secretary

**APPENDIX 3: MINISTRY OF HEALTH APPROVAL**



**All communications should be addressed to:**

The District Community Medical Officer  
Telephone: +260 21 5 221615  
Facsimile: +260 21 5 223505  
Email: kabwedhmt@yahoo.com

reply please quote:  
NO:



**REPUBLIC OF ZAMBIA**  
**MINISTRY OF COMMUNITY DEVELOPMENT MOTHER AND CHILD**  
**HEALTH**

---

**KABWE DISTRICT COMMUNITY MEDICAL OFFICE**

**P.O. Box 80735 TEL: 05 221615 FAX: 05 223505 KABWE**

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20<sup>th</sup> April, 2015

Joyce Chali Mwale  
House No. 285  
Nyumba Yanga



Dear Ms Mwale,

**RE: REQUEST TO CONDUCT RESEARCH IN KABWE DISTRICT.**

I refer to your letter dated 17<sup>th</sup> April 2015 in which you were requesting to conduct a study in Kabwe District.

I wish to inform you that permission has been granted to you. Ensure that the results are shared with Kabwe District Health Management Team and are used as stated in your letter.

Yours Faithfully

A handwritten signature in black ink, appearing to be "Tiza Mufune".

Dr Tiza Mufune

**APPENDIX 4: ~~KABWE DISTRICT COMMUNITY MEDICAL OFFICER~~**

## APPENDIX 5: REQUEST LETTER

17<sup>th</sup> April 2015

House No. 285

Nyumba Yanga

Off Godfrey Chitalu Rd,

Lusaka.

The District Director of Health,

Kabwe District Health Management Team,

Kabwe

Dear Sir/Madam

**Re: Application Letter for permission to conduct and involve your staff and patients in the study in Kabwe District Health Centers**

My name is Joyce Chali Mwale. I am currently a student at the University of the Western Cape in South Africa studying for the Masters in Public Health. The research study is a requirement as a partial fulfillment of the Master's degree in Public Health.

My research is a qualitative study and it will focus on the Factors Affecting Retention in Care of Patients on Antiretroviral Treatment in the Kabwe District, Zambia. The study sites will be Katondo, Makululu and Ngungu clinics, involving patients who are currently on Antiretroviral Therapy (ART), patients who have discontinued ART treatment, Health care professionals and adherence support workers. The research study will provide a better understanding of the factors influencing patient retention in care in the ART program of the Kabwe district. The results of this study will be shared with your organisation as a way of enhancing knowledge in the area of ART retention in care.

I am aware of your organization's active involvement in supporting ART programs in Kabwe district. I am once again requesting your office for permission to conduct and

involve your health staff and patients in my study in the mentioned health facilities above. I have done all that you instructed me to do regarding approvals as you stated in the attached letter. I have now been cleared by the University of the Western Cape, the Zambian Ethics Review Board (ERES Converge Review Board), and the Permanent Secretary at Ministry of Health as shown in the attached letters.

Your assistance in this matter will be highly appreciated.

Yours Sincerely,



Joyce Chali Mwale



## **APPENDIX 6: INTERVIEW GUIDE FOR PATIENTS CURRENTLY ON ART PROGRAM**

1). Kindly tell me about yourself (age, marital status, education, employment, any source of income etc.)

2). When did you start taking ARV treatment?

3). What is the distance from where you live to the clinic? Probe more on:

- What is the means of transport do you use when coming to the clinic?

4). What do you think of the services you receive at this clinic? Probe

- Do you pay for any of the HIV related services at this clinic?
- Do other patients pay for any of the HIV related services at this clinic?
- Has there ever been a stock out of ARV drugs at this clinic?

5) Please tell me more about your experiences with finding help to receive ART at your health facility? Probe for:

- Handiness of the health facility to meeting the ART needs of patients
- Relationship between health workers and patients
- Availability of drugs
- Availability of health workers

6). Have you ever had any experience of being treated differently because of your HIV status? Probe on: Family; at work; at the church; community or in this clinic?

- If yes, kindly tell me the kind of stigma.
- What do you think could be done to improve this?

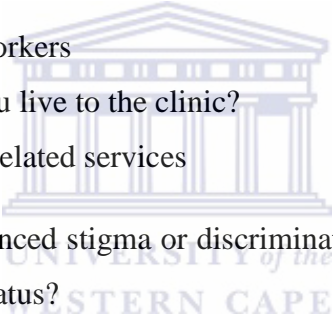
7). In your own opinion, do you think there any religious beliefs that hinder patients from continuing with the use of ART? If yes, could you describe those religious beliefs?

8). What do you think could be the biggest problems why most patients who start on ARV treatment later stop taking their medication? Probe:

9). What do you think should be done in order to ensure that persons who start on ART program at this clinic do not discontinue treatment in the long run?

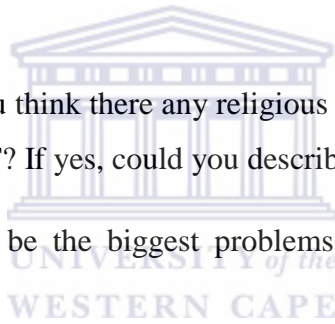


## **APPENDIX 7: INTERVIEW GUIDE FOR PATIENTS WHO DEFAULTED FROM ART PROGRAM**

- 1). Kindly tell me about yourself (age, marital status, education, employment, any source of income etc.)
- 2). When did you start taking ARV treatment?
- 3). When did you stop taking ARV treatment?
- 4) What made you decide to stop taking your ARV treatment? Probe:
  - Handiness of the health facility to meeting the ART needs of patients
  - Relationship between health workers and patients
  - Availability of drugs
  - Availability of health workers
  - Distance from where you live to the clinic?
  - Pay for any of the HIV related services
- 5). Did you at any time experienced stigma or discrimination in the community or at this clinic as a result of your HIV status?
  - If yes, kindly tell me the kind of stigma.
  - What do you think could be done to improve this?
- 6). In your own opinion, do you think there any religious beliefs that hinder patients from continuing with the use of ART? If yes, could you describe those religious beliefs?
- 7). What do you think could be the biggest problems why most patients stop ARV treatment? Probe:
- 8). What do you think should be done in order to ensure that persons who start on ART program at this clinic do not discontinue treatment in the long run?

## **APPENDIX 8: INTERVIEW GUIDE FOR KEY INFORMANTS (COMMUNITY AND HEALTH CARE WORKERS)**

- 1). What is the means of transport do most patients use when coming to the clinic?
- 2). Do patients pay for any of the HIV related services at this clinic?
- 3). Has there ever been a stock out of ARV drugs at this clinic?
- 4). How many staffs are designated to provide ART services at this clinic on a typical HIV clinic day? Probe on: number of staff; type of cadre
- 5). How are the retention rate for ART patients at this clinic?
- 6). What do you think could be the reasons why PLWHA started on ART treatment later discontinue their medication?
- 7). In your own opinion, do you think there any religious beliefs that hinder patients from continuing with the use of ART? If yes, could you describe those religious beliefs?
- 8). What do you think could be the biggest problems why most patients stop ARV treatment? Probe:
- 9). What do you think should be done in order to ensure that persons who start on ART program at this clinic do not discontinue treatment in the long run?



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### APPENDIX 9: PARTICIPANT INFORMATION SHEET

**Project Title:** Factors Affecting Retention in Care of Participants on Antiretroviral Treatment in the Kabwe District, Zambia.

**Principal investigator:** My name is Joyce Chali Mwale. I am a student studying Masters in Public Health at the University of the Western Cape in South Africa. I am working in Zambia for a non-governmental organization called Jhpiego.

**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 Kabwe 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

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the needs of patients and may be efficient in increasing patients' retention on the ART program in the Kabwe 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.

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### **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 Kabwe 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?**

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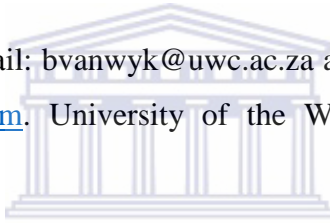
If you have any questions about the research study itself, please contact Ms. Joyce Chali Mwale at: Jhpiego Zambia, 8 Ngumbo Road, Long acres. P.O Box 36873, Lusaka. Cell Phone: +260 977-820 858; Email: [joyce.mwale@jhpiego.org/jomwale2011@gmail.com](mailto:joyce.mwale@jhpiego.org/jomwale2011@gmail.com)

Should you wish to report any concerns or problems you have experienced related to the study, please contact:

**The** Zambian ethics committee, ERES Converge IRB at number 33 Joseph Mwilwa Road, Rhodes Park, Lusaka. Telephone +260 955 155 633 or +260 955 155 634; Cell: 0966 765 503; Email: [eresconverge@yahoo.co.uk](mailto:eresconverge@yahoo.co.uk).

### **OR my project supervisors**

Professor Brian Van Wyk; Email: [bvanwyk@uwc.ac.za](mailto:bvanwyk@uwc.ac.za) and Mr. Ferdinand Mukumbang, Email: [mukumbang@gmail.com](mailto:mukumbang@gmail.com). University of the Western Cape Private Bag X17 Bellville 7535, South Africa.



**OR** the Director (SOPH): Prof Helene Schneider, School of Public Health, University of the Western Cape, Private Bag X17, Bellville 7535, [hschneider@uwc.ac.za](mailto:hschneider@uwc.ac.za). You may also contact the Dean of the Faculty of Community and Health Sciences: Prof Jose Frantz, University of the Western Cape, Private Bag X17, Bellville 7535, [chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za).

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This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee as well as by the Zambian Ethics Committee, ERES Converge IRB.



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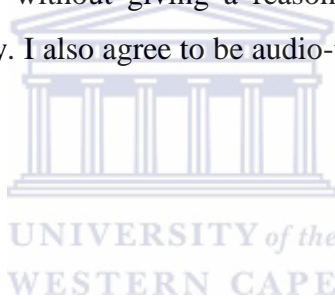
### APPENDIX 10:

### CONSENT FORM

**Title of Research Project:** Factors Affecting Retention in Care of Participants on Antiretroviral Treatment in the Kabwe District, Zambia.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. I have received, read and understood the contents on participant information sheet. My questions about the study have been answered. I understand that my identity and personal details will not be disclosed to anyone and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way. I also agree to be audio-taped during my participation in the study.

Date.....



### APPENDIX 11:

### FOCUS GROUP CONFIDENTIALITY BINDING FORM

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Date.....



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