FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG HIV POSITIVE ADOLESCENTS AT ADULT INFECTIOUS DISEASES CENTER IN LUSAKA, ZAMBIA

BY

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DECLARATION

I **Harrison Chimuka Namoomba** declare that this dissertation represents my own work and all the sources of information have been indicated and acknowledged by means of complete references. I further declare that this dissertation has not previously been submitted for a degree or other qualifications at this or another University. It has been prepared in accordance with the guidelines for Master of Science in Clinical Nursing Dissertation of the University of Zambia.

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I, **Dr. Marjory Makukula Kabinga** having supervised and read this dissertation is satisfied that this is the original work of the author under whose name it is being presented. I confirm that the work has been completed satisfactorily and approve it for final submission.

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APPROVAL

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ABSTRACT

Adherence to combination antiretroviral therapy leads to restoration of the immune function and reduces HIV-related adverse outcomes. However non adherence to combination antiretroviral therapy has eroded this advantage leading to increased morbidity and compromised quality of life among HIV positive adolescents. The aim of this study was to assess factors influencing adherence to combination antiretroviral therapy among HIV positive adolescents at Adult Infectious Disease Center in Lusaka, Zambia.

A descriptive quantitative cross sectional study was conducted on 173 HIV positive adolescents on antiretroviral therapy who were selected using a systematic random sampling method to ascertain factors influencing adherence. Data was collected using the structured interview schedule and analyzed using Statistical Package for the Social Sciences software, version 20. Chi square and fishers' exact statistical tests to determine the association among dependable and independent variables and binary logistic regression was used to determine true predictors and to adjust confounders of adherence. The cut off point for statistical significance was set at 5%.

This study established that 76(43.9%) of the respondents were found to be non adherent to their antiretroviral therapy. The study identified that stigmatization was high 99(57.2%) but did not significantly influence adherence to combination antiretroviral therapy on the study participants. Knowledge of HIV and disease progression was reported to be low but this did not have any statistical impact on antiretroviral therapy adherence. Factors which were found statistically significant for adherence to therapy when a binary logistic regression was performed were experiencing side effects to therapy (p-value 0.047, odds ratio= 0.412); Understanding reason for taking combination antiretroviral therapy (p-value 0.006, odds ratio= 5.978) and Being reminded to take drugs (p-value 0.006, odds ratio= 0.505).

The study found that there was high level of non adherence to combination antiretroviral therapy which could in turn lead to emerging of more cases of treatment failure. More studies on factors influencing non adherence to combination antiretroviral therapy need to be conducted to develop evidence based impact based practice model for HIV positive adolescents care.

Key words: knowledge, treatment failure; antiretroviral drugs, non adherence to cART, Cultural beliefs, social support and stigmatization.

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DEDICATION

I dedicate this study to the children living with HIV/AIDS who have demonstrated the bravery spirit to live with the chronic illness in the most positive and high spirited manner in Zambia and across the world. Special people for their immense contributions in my academic endeavor and thanks going to the following:

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DEFINITION OF CONCEPTS

Knowledge: Knowledge refers to the fact or condition of knowing something with familiarity gained through experience or association (Merriam Medical Dictionary, 2017).

Social support: This is the physical and emotional comfort given to a person by family, friends, coworkers or others (Nichole, 2011)

Adherence to cART: This is a term used in the context of cART treatment and to means taking all the prescribed drugs for 95% or more times as prescribed (WHO, 2013).

Treatment failure: Failure of complete viral load suppression, or development of progressive immunodeficiency marked by CD4 T lymphocyte (CD4) cell depletion, and clinical AIDS-defining illnesses and premature death in the HIV-infected individuals, despite being on antiretroviral therapy for six month or more (PAGAA, 2016, WHO, 2013).

Antiretroviral drugs: These are drugs that inhibit the reproduction of retroviruses-viruses composed of RNA rather than DNA. The best known of this group is HIV, human immunodeficiency virus, the causative agent of AIDS (WHO, 2015).

Adolescent: An adolescent is a person in the period of developmental maturation between the age of 12 and 19 years (Columbia Electronic Encyclopedia, 2013).

Retention in care: This represents the process of ongoing participation in HIV medical care, while medication, adherent to taking medications, corresponds with agreed recommendations from a health care provider (WHO, 2015).

Treatment failure: will mean an occurrence of notable none response to otherwise highly effective prescribed cART in a patient after 6 months of treatment

Knowledge: This will refer to the HIV positive adolescents that will be aware of information regarding HIV treatment and disease progression. In this study, if the HIV positive adolescent will be able to correctly answer 12 or more questions on knowledge will be regarded to have a high level of knowledge. An adolescent will be said to have low level of knowledge if they answer 1 to 11 questions on knowledge correctly.

Social support: This will refer to the extent at which the HIV positive adolescents will feel supported emotionally, receive some practical assistance, sharing view points and information sharing by family members and social groupings with regards to HIV treatment and care.

Adherence to cART: This will mean adolescent being able to answer correctly all the responses on the 4 item Morisky drug compliance scale within the past one month from the date of data collection.

Religious beliefs: This will be interpreted as having a positive or negative commitment to a belief system or religious beliefs about HIV cure.

Adolescent: A young person between 12- 19 years of age who depends on elderly person for any health related decision making.

Retention in care: being able to continue with stipulated instructions and requirements of one's care by the health provider

ACRONYMS

AIDS	:	Acquired Immune Deficiency Syndrome
ART	:	Anti Retro-viral Therapy
cART	:	combination Anti Retro-viral Therapy
ARVs	:	Antiretroviral
CI	:	Confidence Interval
CIDRZ	:	Centre for Infectious Diseases Research in Zambia
CSO	:	Central Statistical Office
SNS	:	School of Nursing Sciences
H_0	:	Null Hypothesis
H_i	:	Alternative Hypothesis
HIV	:	Human Immuno-deficiency Virus
MoH	:	Ministry of Health
SPSS	:	Statistical Package for Social Sciences
UNAIDS	:	United Nations Programme on HIV/AIDS
UNICEF	:	United Nations Children's Fund
UNZABREC	:	University of Zambia Biomedical Research Ethics Committee
UTH	:	University Teaching Hospital
WHO	:	World Health Organization
UNZA	:	University of Zambia
CD4	:	Cluster of Differentiation 4
SEM	:	Social Ecological Model

RNA	:	Ribonucleic acid
DNA	:	Deoxyribonucleic acid
PAGAA	:	Panel on Antiretroviral Guidelines for Adults and Adolescents
AIDC	:	Adult Infectious Diseases Center
NVP	:	Niverapine
EFV	:	Efavurenz
ABC	:	Abacavir
TDF	:	Tenofovir
XTC	:	Emitricitabine/Lamivudine
CDC	:	Centers for Disease Control and Prevention
MTCT	:	Mother to Child Transmission
FHI	:	Family Health International
PIDC	:	Pediatrics Infectious Diseases Center
ART	:	Antiretroviral Therapy
USA	:	United States of America
WMA	:	World Medical Association
DHMT	:	District Health Management Team
DRGS	:	Directorate of Research and Graduate studies

CHAPTER ONE: INTRODUCTION

1.1 Background Information

Adolescents represent an increasing number of people living with Human Immune-deficiency Virus (HIV) worldwide. In 2015, 1.8 million adolescents between ages 15 to 19 were living with HIV (United Nations Children's Fund (UNICEF, 2015). To mitigate the impact of HIV infection adolescents tested positive regardless of consideration CD4 count or world health organization (WHO) clinical staging, are commenced on combination of antiretroviral therapy (cART) (WHO, 2013).

With adherence to cART of 95% or more HIV-associated morbidity and mortality are reduced leading to restoration of immune function hence, transformation of HIV infection into a manageable chronic condition (WHO, 2013; Centers for Disease Control and Prevention [CDC], 2014). However, benefits of long quality productive life, reduced opportunistic infections among HIV positive adolescents are generally eroded because of non adherence to cART. Non adherence to cART has been linked to drug resistance, unsuppressed viral load, associated morbidity and mortalities (Desalegn et al, 2015; Panel on Antiretroviral Guidelines for Adults and Adolescents [PAGAA], 2016). Therefore, this study focused to determine factors influencing adherence to cART among adolescents at Adult Infectious Diseases Centre (AIDC) in Lusaka, Zambia.

HIV and AIDS have continued to affect young people despite significant scientific advances in prevention and treatment (UNAIDS, 2011). In 2015, 1.4 million (80%) adolescents living with HIV globally were in Sub-Saharan Africa (WHO, 2013; UNICEF, 2015). The Central Statistical Office (CSO) Zambia (2015) reported that about 4.4% of the adolescents aged 15-19 years in Zambia had HIV infection. According to Kankasa et al (2011) about 4,000 children were initiated on cART from the UTH, Pediatrics and Adult Infectious Diseases Centers program. Evidence has shown that HIV positive adolescents could have acquired the infection perinatally or in infancy through breastfeeding (UNICEF, 2015; PAGAA, 2016). Agwu et al (2012) indicated that the majority of adolescents acquired HIV through mother to child transmission (MTCT) and about 18% got infected later in their lives. The WHO (2013) treatment guidelines recommended combination antiretroviral therapy (cART) initiation to all HIV infected adolescents to prevent HIV-related morbidity and mortality. Chkhartishvili et al (2014) equally noted that access to cART to treat HIV infection and AIDS in resource-poor countries had improved over the past several

years. The cART when taken correctly could lead to sustained viral suppression and reduction in occurrence of AIDS-defining and non-AIDS-defining complications. In order to achieve sustained viral suppression and clinical benefits WHO (2016) further emphasized strategies such as; early diagnosis and treatment, adherence to cART counseling and viral load monitoring among others to all HIV positive adolescents.

Adolescents diagnosed with HIV are started on cART to achieve complete viral suppression and prevention of occurrence of treatment failure later in their life (UNICEF, 2015; PAGAA, 2016). Other authors have stated that incomplete viral suppression could lead to treatment failure especially among the adolescents (Paredes et al, 2010; WHO, 2016). To achieve complete viral suppression and prevention of treatment failure, the WHO (2017) guidelines recommended first, second and third line streams of cART from which treatment for the HIV positive adolescents could be commenced. First line cART regimen is initiated by providing an optimized, fixed-dose cART regimen of Tenofovir (TDF) + Lamivudine/Emitricitabine (XTC) + Efavirenz (EFV)/Nevirapine (NVP) or Abacavir (ABC) + XTC + EFV (weight based dosing) for adolescents.

Once treatment is commenced, enhanced adherence to cART for individual HIV positive adolescent patients have been emphasized (WHO, 2013; MoH, 2014). According to CDC (2016) adherence has been strongly correlated with HIV viral suppression, reduced rates of drug resistance, enhanced survival and improved life expectancy among HIV positive adolescents.

The routine viral load monitoring is recommended as the most accurate objective available measure to determine effective cART response (Edward et al, 2016; WHO, 2013). Detectable viral load exceeding 1,000 copies/ml on two consecutive measurements within a three-month interval, with enhanced adherence support between measurements after at least six months of using first line cART, the adolescent would be said to have developed Virologic treatment failure. Virologic failure requires that the patients are switched to second line treatment (MoH, 2014). Lopinavir boosted by ritonavir (LPV-r) is primarily the recommended second line choice regimen for HIV positive adolescents. Provision of third line cART occurs in very rare circumstances and is beyond the scope of most cART providers (MoH, 2014; PAGAA, 2016).

Despite the emphasis on measures to prevent AIDS-defining complications and optimal cART provision, some studies have reviewed that non-adherence to cART among adolescents has remained prevalent (Edward and Klatt, 2016; UNICEF, 2015; WHO, 2013; PAGAA, 2016; Buchanan et al, 2012; Mulenga et al, 2015; Katayamoyo et al, 2016). Other authors have linked non-adherence to cART among adolescents to persistently elevated viral loads and progression of HIV infection into AIDS defining illnesses (Ryscavage and Anderson, 2011; Melsew et al, 2013). While reasons for cART non-adherence are not clear, several factors have been implicated and these include Social cultural beliefs, lack of social support and stigmatization among others. Baggini (2011) reported that some social cultural beliefs impact negatively on conversional drugs adherence which could result in poor treatment outcomes. Snyder (2014) found that lack of social support for HIV positive adolescents from the caregivers, friends, or clinicians could lead to non-adherence to cART resulting in virologic treatment failure. UNICEF (2012) also showed that overall level of comprehensive correct knowledge of HIV and AIDS remains very low among older adolescents aged 15-19. Xu et al (2017) however, found that HIV-infected adolescents demonstrated good knowledge regarding HIV/AIDS and cART, including the consequences of developing drug resistance with suboptimal cART adherence. Despite some reports in studies that HIV positive adolescents have good knowledge regarding HIV/AIDS progression, non-adherence to cART and treatment failure have remained prevalent in this age group. Non-adherence to cART have been linked to treatment failure which defeats the primary goals of cART provision of maximal and durable suppression of viral load, restoration and preservation of immunologic function, improvement of quality of life, and reduction of HIV-related morbidity and mortality as cited by MoH (2014) and PAGAA (2016).

The required level of 95% cART drug adherence leads to viral suppression when ARV drugs are used as prescribed, and for life (Ciaffi et al, 2015). Non-adherence to cART causes transmutations of the virus and later drug resistance (Carter, 2012). The transmutations of the HIV and drugs resistance leads to switching of regime to second or third line therapy, which rapidly exhaust the cART available options resulting in AIDS defining morbidities and mortality among HIV positive adolescents (WHO, 2013). To prevent cART failure, intrapersonal and interpersonal related factors which could be linked to non-adherence to cART among adolescents need to be clearly

investigated. Therefore, this study assessed adherence and investigated factors influencing adherence to cART among the HIV positive adolescents.

1.2 Statement of the Problem

Existing studies have documented non-adherence to cART among HIV-infected adolescents globally and regionally (Xu *et al*, 2017; Mulenga *et al*, 2015). In Zambia, Family Health International (FHI) 360, (2013) reported that 22% of adolescents living with HIV missed two or more days of their cART in the previous three months. Other authors have concluded that missing cART drugs for two or more consecutive days increased the risk of virologic failure, resistance to ARV drugs and subsequent regime change due to occurrence of treatment failure (Buchanan *et al*, 2012; Katayamoyo *et al*, 2016).

The UTH, Adult Infectious Diseases Center [AIDC] (2017) showed that over 850 HIV-infected adolescents aged between 16 and 19 years were enrolled on cART. Furthermore, statistics obtained from the AIDC pharmacy revealed that the number of HIV positive adolescents failing cART for the period 2013 to 2016 kept on increasing (Table 1).

Table 1 Adolescents aged 16 to 19 years failing cART at UTH, Adult Infectious Diseases Center in Zambia; **January 2013 to December 2016 record (N= 852)**

		2014	**2015**	**2016**
Treatment Options for HIV-Positive Adolescents	**Second line**	110	170	306
	Third line	32	45	58
	Total	**142**	**215**	**364**

In the same record; adolescents on cART third line option showed a similar pattern of increased number from seventeen (17) patients in 2013 to fifty eight (58) in 2016. These statistics were suggestive of an increase in number of treatment failure cases among the adolescents who were seeking health services at AIDC. The MoH (2014) indicated that provision of third line cART occurred in very rare circumstances and was beyond the scope of most cART providers.

It has been stated that, patients who fail on their treatment regimens rapidly exhaust the available options resulting in AIDS defining opportunistic infections (OIs), increased morbidity and mortalities (WHO, 2013). The OIs are treated with other drugs, a situation that add more pill burden to the HIV positive adolescent patients which results into further non-adherence to cART.

Despite the emphasis on adherence counseling to HIV positive adolescents (MoH, 2014) in the treatment guidelines non-adherence to cART have continued to be a challenge in this age group. Factors which influence adherence to cART among HIV positive adolescents are not clearly understood although some studies have suggested religious beliefs and being away from home at dosing time as the reasons (Mulenga et al, 2015; Katayamoyo et al, 2016). However, the researcher assumed that there were other factors influencing adherence to cART. The assumption was that the factors could be related to individual, interpersonal, organizational/institutional, and community. The study therefore aimed at exploring factors that influenced adherence to cART among adolescents in Zambia.

1.3 Justification

HIV-infected children and adolescents on cART are living longer and have the opportunity to grow up and become productive adults (FHI 360, 2013). However, non-adherence to cART could lead to sustained high viremia, associated with treatment failure, and increased morbidity and mortalities among the HIV positive adolescents.

Several studies have been conducted on adherence to cART on adult HIV positive patients however, few have focused on adolescents. This study therefore assessed adherence to cART and determined factors influencing adherence among HIV positive adolescents. Study brought out factors influencing adherence to cART and findings could be used to develop strategies, improvement of adherence and prevent treatment failure among HIV positive adolescents.

The findings in this study could be used in planning for future interventions to promote adherence to cART among the special population of the adolescents. This could promote retention and maintenance of the HIV positive adolescents on available treatment options for as long as possible without depletion of future regimens. Results of the study have also added to the body of knowledge on HIV and created a basis for further studies on adherence to cART among HIV positive adolescents.

1.4 Theoretical Framework

The factors influencing adherence among HIV positive adolescents were investigated from the Social Ecological Model (SEM) theoretical perspective of Individual, Interpersonal, Organizational/Institutional, and Community Levels. The SEM theoretical perspective stresses that individual behavior is influenced by factors at different levels as classified by Sallis and Owen (2002) (Figure 1).

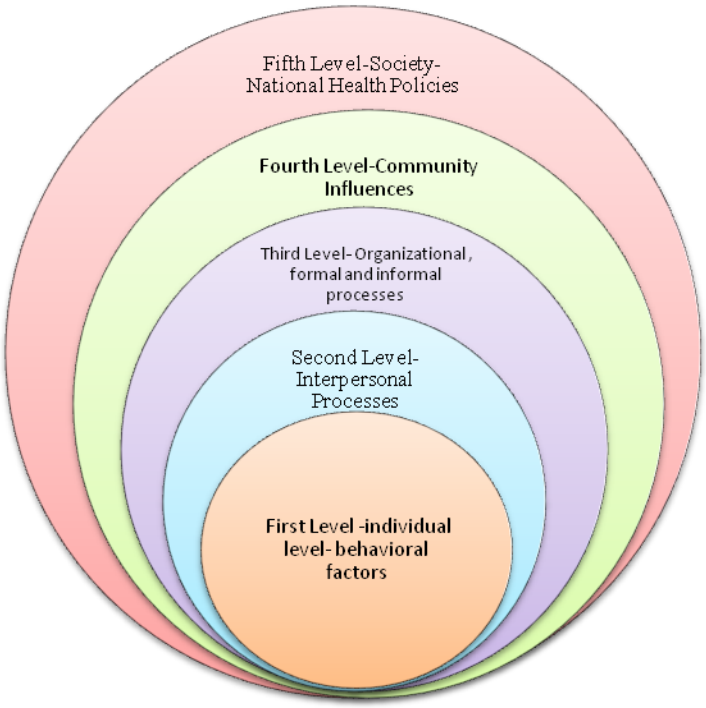

Figure 1: Social Ecological Model (*Adapted from Sallis and Owen, 2002*)

1.4.1Theoretical constructs of the Social Ecological Model

The SEM recognizes the interdependences that exist between individual, interpersonal, organizational, and societal determinants to health related behavior (Sallis and Owen, 2002). The model emphasizes that individuals should be responsible for instituting and maintaining practices necessary to reduce risk and improve health. However, when the interdependence balance is disturbed at any level, the risk of ill health also increases. The interdependence could be summarized in the following SEM five levels;

First level: Individual processes, includes the characteristics that influence a persons' behavior such as age, knowledge, attitudes, skills, and beliefs.

Second level: Interpersonal processes provide social identity and role definition such as social support systems, parents, friends, and school mates.

Third level: Organizational processes include rules, policies, and formal and informal structures.

Fourth level: The community has established norms and values system, religious beliefs, and social networks which could positively or negatively impact on the health of its members.

The Fifth level: Societal processes include cultural context and national policies on health.
The major strength of the SEM in the current study was that it was possible to identify factors from each level which influenced adherence to cART among the HIV positive adolescents at the Adult Infectious Diseases Center in Lusaka, Zambia.

1.4.2 Application of the Social Ecological Model in this study

There could be several factors that influence adherence to cART among HIV positive adolescents. In this study first level individual, second level interpersonal, third level organizational and fourth level community processes related factors were investigated (Figure 2).

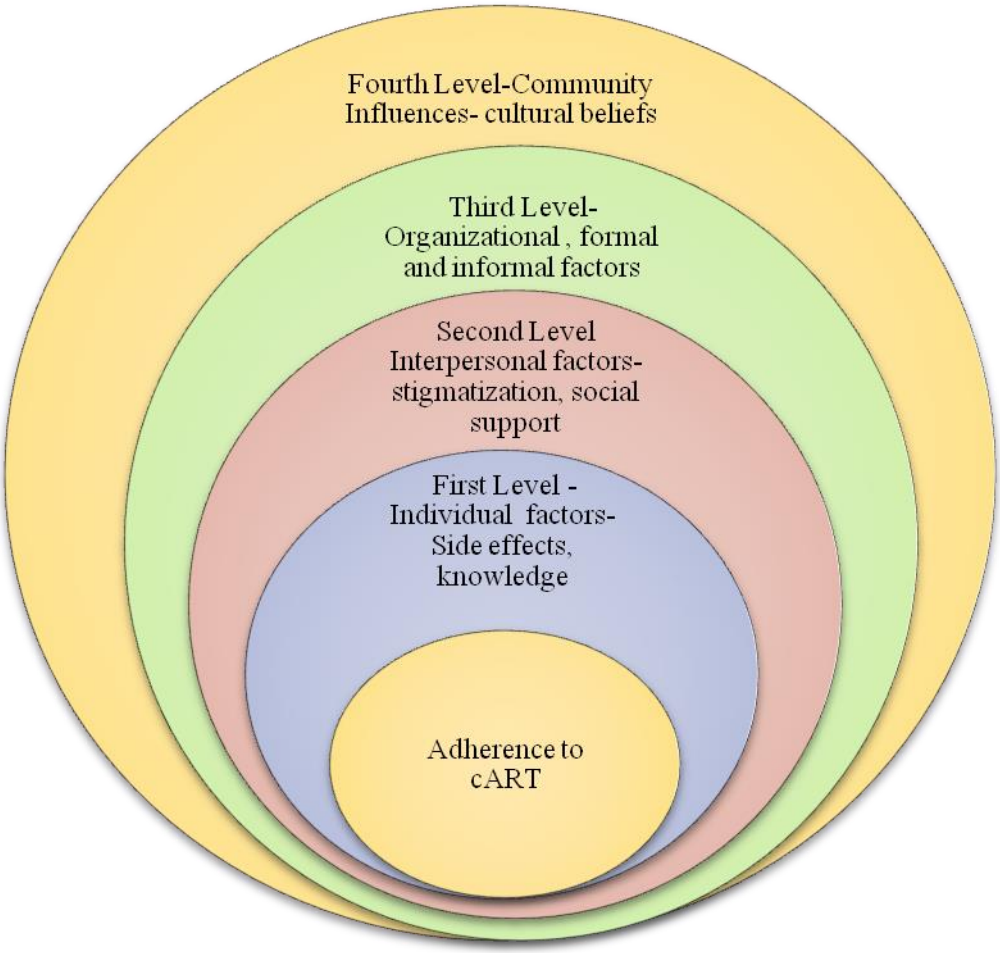

Figure 2: Adapted SEM applied on the HIV positive adolescents' adherence to cART.

1.4.2.1 Individual Level

Poor knowledge level and lack of understanding of the benefits for taking cART could result into non-adherence among HIV positive adolescents. HIV positive adolescents are more likely to question their cART lifelong treatment and express regimen fatigue when they possess limited knowledge about the HIV disease process or reason for staying on therapy indefinitely. Therefore, lack of knowledge could be associated with non-adherence to cART and subsequently lead to persistently high viral loads among the HIV positive adolescents.

Experiencing cART side effects

The medications used in second-line cART are rarely tolerated by patients due to toxicity such as hypersensitivity reaction; kidney failure; progressive neuropathy and gastrointestinal complaints. Ciaffi et al (2015) also observed that toxicities and side effects due to medication often prompted non-adherence to cART among HIV positive adolescents.

1.4.2.2 Interpersonal related factors to cART failure

Social support: HIV positive adolescents expect to get some support from other people as they take the lifelong cART. According to Bygrave et al (2012), Social support could be in different forms which include;

Emotional support: this is where the HIV positive adolescents feel encouraged by others around them to continue with cART and all the clinical follow ups as scheduled. Adolescents lacking emotional support are more likely to be non-adherent to cART because they may feel depressed and separated from others.

Sharing of information: The relative lack of healthcare professionals, (trained Adolescent treatment supporters, Psychologists, Social workers, and Counselors) experienced in adolescent healthcare management further impact negatively on the cART adherence outcomes for HIV-infected adolescents in resource limited settings. It is very helpful for the HIV positive adolescents to be given information from healthcare professionals, family, friends about factual and meaningful HIV disease progression and what to expect when treatment plans are not followed.

Sharing the view points: It is important to approach the HIV treatment failure among the adolescents from their view point perspective of the disease. Listening to HIV positive adolescents' opinions about how they view the problem of non-adherence to cART offers better understanding of their experiences.

Stigmatization

The HIV positive adolescents may fail to take cART because of their friends being around especially those confined in the boarding schools set up. This can lead to self-imposed stigmatization by the HIV positive adolescents fearing that they could be rejected by the friends if discovered taking the cART for HIV infection.

1.4.2.3 Organizational/ Institutional related influences

1.4.2.4 Formal and informal processes

In most instances the adolescent ART services are formally integrated with those of the adults. This makes the adolescents to be uncomfortable in the presence of other adult patients, making it difficult to retain them in care. When HIV positive adolescents are not retained into care, they will not access the cART and this could lead to reduced adherence to the medications.

1.4.2.5 Community related influences on HIV positive adolescents to cART treatment Failure

Religious beliefs

The Community has cultural beliefs, Practices, norms and values, social networks and religious beliefs that could influence positively or negatively on the HIV positive adolescents care. According to Andrews and Boyle (2016), there are religious groupings within the communities with the belief that anointing oil and prayers can be used to heal diseases. This belief system has a potential to have HIV positive adolescents abandon the prescribed cART hence increasing the risk of drug resistance and treatment failure.

1.5 Research question

What factors influence adherence to cART among HIV positive adolescents?

1.6 Research objectives

1.6.1 General objective

To explore factors Influencing adherence to cART among HIV positive adolescents.

1.6.2 Specific objectives

a) To determine adherence to cART among HIV positive adolescents.
b) To assess the level of knowledge on antiretroviral therapy and HIV disease process among HIV positive adolescents.
c) To determine the social cultural factors which influence adherence to cART among HIV positive adolescents.

1.7 Hypothesis

***1.7.1 Null Hypothesis (H_0)*:** There is no relationship between adherence to cART among HIV positive adolescent and the following variables:

i. Knowledge of cART treatment and disease process
ii. Social cultural factors

1.8 Variables

The two categories of variables in this study are the dependent and independent variables. A dependent variable is the outcome or effect or response to the independent variable, whereas the independent variable is a variable that influences the dependent variable. The following are variables used in this study:

1.8.1 Dependent variables

- Adherence to cART

1.8.2 Independent variables

- Knowledge
- Stigmatization
- Social support
- Religious Beliefs

Study variables for this study which include; knowledge, drug adherence social support, cultural beliefs and cART treatment failure will be operationalized (Table 2).

Table 2: Research Variables, Indicators and Cut off Points

Variables	Indicators	Cut Off Point	Question (Q) Numbers
Dependent variable			
Adherence to cART	Adherence Non adherence	Answering YES to all 4 questions Answering NO to any one or more questions	 8 to 11
Independent variables			
Knowledge about HIV and disease progression	High Low	12 scores and above of 1 to 11 scores	12 to 28
Social support	Adequate Inadequate	5 scores and above Less than 4 scores	29 to 37
Religious beliefs	Positive Negative		38 to 41
Stigmatization	High Low		42 to 45

CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

This chapter presents a comprehensive appraisal and analysis of the existing body of literature related factors influencing adherence to cART among the HIV positive adolescents. According to Creswell (2014), literature review should be conducted to find similar studies to the problem under study. This leads to generation of ideas on information available about the topic, identification of gaps in the existing researches and prevent unintentional duplication.

Literature was reviewed using various search engines and systematic searches were undertaken. The search was done and not limited to the MEDLINE, EBSCO academic online library, Google Scholar, PubMed, Hinari, Journal for International AIDS Society and many more. Period restrictions in most cases were placed on the search engine to extract only relevant up-to-date evidence. Key search terms include knowledge, treatment failure; antiretroviral drugs, non adherence to cART, Cultural beliefs, social support and stigmatization.

2.2 Overview of Adherence to cART among Adolescents

The Global initiatives have ensured universal access to cART to a large number of HIV patients including adolescents in resource-poor countries (WHO, 2013). The United Nations Programme on HIV/AIDS [UNAIDS], (2014), global initiative set new targets towards elimination of HIV. The targets were aimed at diagnosis of 90% of HIV infected individuals, access to treatment of 90% diagnosed HIV infected persons, and to achieve 90% viral suppression to those initiated on treatment. These targets have since been adopted by several countries including Zambia. For cART programmes to be successful adherence is one key measure to achieve viral suppression. Thus, viral load is a critical indicator for HIV treatment success and quality of progress towards national and global indicators. Despite advances in effectiveness and availability of cART, non adherence among adolescents has remained a major threat to attaining the 90% viral suppression global and national targets which consequently could results in treatment failure (UNAIDS, 2014).

Ryscavage et al (2011) conducted a study on the Clinical outcomes of adolescents and young adults in adult HIV care in the United States of America (USA). The study found that HIV positive adolescents were less likely to be adherent to cART and achieve viral suppression, compared with the HIV-infected adults. The reasons for these clinical outcomes and non adherence to cART by the HIV positive adolescents were not clear. Some scholars have concluded that 95% or more of

adherence to cART is crucial for successful viral suppression (Boussari, 2015).This is because incomplete adherence leads to an increase in HIV viremia, risk of treatment failure, and accumulation of resistance viral mutations (Konstantopoulos et al, 2015)

According to Ryscavage et al (2011) in the USA, HIV positive adolescents have challenges with attaining and sustaining the recommended 95% threshold of cART adherence. In a study to estimate rates of virologic failure Kyaw et al (2015) found that 34% of the adolescents had virologic failure. The virologic failure was strongly associated with just being of adolescence age and non adherence to cART. Though the study did not indicate the factors linked to non adherence to cART. Similarly, Kanabkaew et al (2017) found that 48.4% of the adolescents had evidence of suboptimal adherence to cART.

In sub-Saharan Africa, non adherence to cART has been reported. Muri et al (2017) conducted a study to assess the development of HIV drug resistance and therapeutic failure among adolescents in Tanzania. It was concluded that virologic failure rates among adolescents was high due to non adherence and perceived this as an emerging public health concern. Equally, Nglazi (2012) reported that HIV infected adolescents in South Africa had worse outcomes of virologic suppression. This was due to non adherence to cART and rate of mortality compared to the adult counterparts was found high. In Zambia, Katayamoyo et al (2016) found that there was suboptimal adherence to cART mainly due to increase in age as the main contributing factor. The factors that lead to non adherence to cART are not universally understood. However, several factors have been implicated and these are discussed below.

2.3 Factors Influencing Adherence to cART among Adolescents

2.3.1 Knowledge of HIV positive adolescents on HIV and disease progression

Inadequate knowledge and lack of understanding of the benefits for taking cART could result into non-adherence among HIV positive adolescents (Agwu and Fairlie, 2013). While some studies have reported high knowledge among HIV positive adolescents few have indicated inadequate knowledge (XU et al, 2017; Hornschuh et al, 2017; Kenu et al, 2014). A mixed method study to determine factors influencing cART suboptimal adherence among perinatally HIV-infected adolescents was conducted in Thailand by Xu et al (2017). It was found that all the HIV positive adolescents' informants demonstrated good knowledge regarding HIV/AIDS and ART, including the consequences of developing resistance with non adherence. Similarly Hornschuh et al (2017)

reported that most HIV positive adolescents had accurate basic knowledge about how to take their ARVs and know that the medication schedule should be followed as prescribed. However, though correct information about dosing was known to the adolescents, the rationale for the dosing schedule and HIV disease progression was not known.

A study conducted by Kenu et al (2014) in Ghana found that 47% of adolescents who were taking the cART had no knowledge about the HIV disease and its progression. Similar findings were reported by Mweemba et al (2015) in Zambia. The study found that 56.7 % of the adolescents had knowledge about their HIV status. In the same study it was also reported that HIV status disclosure was enabler for adolescents' acquisition of knowledge about HIV. However, caregivers had some fear to disclose the HIV status to the adolescents. This was attributed to perceived psychological trauma for the adolescents and perceived inability of adolescents to keep their HIV status confidential. Inability for the HIV positive adolescents to keep their status confidential could attract stigmatization and blame for the infection.

2.3.2 Social cultural factors

2.3.2.1 Social support system

Lack of social support system is another factor that could lead to non adherence to cART. According to WHO (2011) social support has been identified to improve patient's mental health status and the ability to improve ART adherence. Lee et al (2015) found that HIV positive youths who had received social support, had higher levels of perceived overall good adherence to cART**.**

Given the strong relationship between adherence and virological suppression, it is important that HIV positive adolescents have access to social support systems that would help them adhere to cART. However, some HIV positive adolescents are not living with parents or caregivers and thus do not reap the benefits of family support system (Kahana et al, 2013). There is a need for more holistic, multi-faceted adolescent-friendly services to provide the necessary social support. A Canadian involving HIV positive adolescents taking part in a 12-week educational program with family members appeared to have been useful adherence intervention. This was attributed to strong family relationships built suggesting that the presence of guardians or adult role models in the HIV positive adolescents' lives have a mediating effect on adherence levels. It could also mean that for the cART to be successful, social support systems must be strengthened and implemented.

The importance of social support to ART adherence has been highlighted in many sub-Saharan African studies. Fetzer et al (2011) described a strong association between caregiver supervision and cART adherence among adolescents in the Democratic Republic of Congo. Similar associations were been reported in qualitative studies among adolescents with HIV infection and their caregivers in Kenya and South Africa according to Peterson et al (2012) study. Among a sample of South African adolescents, those with extensive supportive networks among relatives and peers appeared to cope better with psychosocial challenges. Caregivers played an important role in facilitating ART adherence. The participants in this study reported that caregivers contributed to their good adherence by reminding them to take their medications. Snyder (2014) study showed similar evidence that HIV-positive adolescents in South Africa, who received social support from the caregivers, friends, or clinicians where more likely to be adherent to cART. Snyder (2014) further reviewed that social support may come in the form of disclosing the adolescents' HIV-status to enhanced remainders of cART support in the communities.

In Zambia, a study by Mburu et al (2014) on barriers to disclosure of HIV status found that disclosure had various outcomes at the individual and interpersonal levels. At the individual level, some adolescents described being anxious, depressed and blaming themselves after being told they had HIV and this could consequently lead to non adherence to cART. At the interpersonal level, disclosure created opportunities for adolescents to access adherence support and other forms of psychosocial support from family members and peers. In this regard disclosure becomes a prerequisite to any form of meaningful social support for HIV positive adolescents.

2.3.2.2 Religious beliefs

Some beliefs about HIV contribute to fatalistic attitudes and passive resignation, which hinders participation in treatment. In one study from rural Mali conducted by Hess et al (2012), because of prevailing beliefs in that region, HIV positive adolescents also had a similar belief that AIDS was a punishment from God and had more fatalistic attitudes. Example agreeing to the statement "I believe that if a person has HIV/AIDS most treatments will not change anything". It could also be concluded that adolescents with such belief system would abandon the cART. The belief that prayer can cure HIV may also challenge adherence to cART programs. A study by Wanyama et al (2013) on ART adherence in Uganda found that 6 out of 558 (1.2%) adolescents discontinued their treatment because they believed that their pastors' prayers had cured them of HIV. Such belief

systems impact negatively on adherence to cART. This could promote reduced therapeutic drug levels in blood leading to resistant viral mutations and virologic treatment failure.

Nozaki et al (2013) in a study conducted in Zambia showed that while 95 % of respondents were aware that they had to take medicine every day for life once they began ART, 17 % of participants falsely believed that HIV could be cured by ART. These two beliefs seem incompatible but were jointly held by 16 % of all respondents, suggesting fundamental misunderstandings of the functioning of ART even after the comprehensive ART counseling and education. Another particularly worrisome false belief is that pastors can cure HIV infection through prayer which was held by 17 % of participants. This would suggest that these patients may at some point decide to discontinue medical treatment and seek cure through prayers. These beliefs could lead to some patients stopping ART after attending prayer services promising to cure their HIV infection.

2.3.2.3 Stigmatization

WHO (2011) stated that disclosing of HIV-positive status by adolescents to friends or family can be a complicated process due to the high levels of HIV-related stigmatization and fear of potential shame. Katz et al (2013) conducted a study in Eastern Europe and Central Asia, found that 61% reported positive findings of stigma. These HIV positive adolescents were associated with reduced ART adherence level. Nabukeera-Barungi et al (2015) conducted a mixed qualitative and quantitative study in Uganda on adherence to antiretroviral therapy among adolescents. The study found that there was significant stigma and discrimination at school by teachers and fellow students. The adolescents in boarding schools lacked privacy to take their cART which lead to missing of some doses. For those who did not disclose their HIV status to the school authorities, it was very difficult to get permission to leave school to keep clinic appointments. This could lead to absenteeism from the clinic and eventually drop out from HIV care. The study also found that the working adolescents did not have job security and perceive that people label them as weak and did not want to employ them. Feldman et al (2012) HIV cohort, longitudinal observational study in USA found that 76% of the young adults had reported experiencing some HIV-related stigma which impacted negatively on their routine taking of the cART.

Mburu et al (2014) in a study conducted in Zambia observed that stigma and discrimination among HIV positive adolescents was encountered in many community settings. The study reported that stigmatization and discrimination based on the HIV status, affected their decisions regarding

disclosure of their status in schools. In particular, stigmatization and discrimination at school greatly affected the experiences of adolescents. Instances were reported of teachers hinting at the presence of students living with HIV in a manner that was interpreted as a warning not to associate with them. When stigmatizing and discriminating statement comes from a teacher who should be regarded as role model in society, the infected and affected adolescents are more likely to abandon cART. This could consequently lead to virologic failure in a long run due to the perceived discrimination and stigmatization.

2.4 Conclusion

Reviewed studies have shown that non adherence to cART exist however, factors which leads to its prevalence are different in most settings among adolescents. Some studies have shown that HIV positive adolescents demonstrate good knowledge regarding HIV/AIDS and ART, including the consequences of developing resistance with suboptimal adherence. Despite knowledge shown in some studies, non adherence to cART among HIV positive adolescents is prevalent in both resources limited and developed settings. The findings from literature reviewed on non adherence to cART in most parts of the world pause a critical challenge in the care of adolescents who are HIV positive. Stigmatization has been implicated by some studies as a non enhancer of adherence to cART among HIV positive adolescents.

Little information currently exists on social support as influencer of the HIV positive adolescents' ability to improve cART adherence to treatment in Zambia. Recent studies have shown evidence that social supported adolescents were likely to be adherent to cART in some parts of the world. This study used the social ecological theoretical framework to explore factors that may influence adherence to cART among HIV positive adolescents.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

This chapter discusses the research design, research setting, study population, target population, sample size and data collection.

3.2. Research Design

The study used a descriptive quantitative cross-sectional research design. The design was selected because data were collected at one point and no interventions or manipulations were carried out on both the environment and the respondents.

3.3. Research Setting

The study was conducted at Adult Infectious Diseases Centre in Lusaka Zambia. The centre offers specialized HIV/AIDS medical care to patients on first, second and third line cART. The AIDC was chosen because it had referred HIV positive adolescent patients from ART care centres from Lusaka and other surrounding districts. It is located in the capital city of Zambia, approximately 5km east of Lusaka town centre (CSO, 2015).

3.4. Study Population

The study population consisted of HIV positive adolescents on cART treatment who receive care at Adult Infectious Diseases Centre, Lusaka.

3.4.1. Target population

The target population were male and female adolescents aged between 16 and 19 years on cART for at least three months enrolled for care at Adult Infectious Diseases Centre. These were adolescents who had transitioned from children's to adult hospital soon after attaining their 16th birthday. Parents and guardians after this hospital transition seem to reduce on accompanying these HIV positive adolescents to the clinical follow up.

3.4.2. Accessible population

The accessible population consisted of HIV positive male and female adolescents between 16 and 19 years who were coming for clinical follow up care at the time of data collection and had agreed to participate in the study.

3.5. Sample Selection

A probability sampling method called systematic sampling was used to select the study sample. A selection of every k^{th} subject on a scheduled booking was requested to participate in the study using N/n. Therefore, every 5^{th} subject of HIV positive adolescents on cART who was coming for scheduled visits was asked to participate in the study (Polit and Hungler, 2013). The starting point was randomly arrived at to reduce biased selection. This method provided all the subjects in the population with equal chance to be included in the study.

3.5.1 Inclusion Criteria

The inclusion criteria consisted of adolescents:

a. On cART aged between 16 and 19 years who were under care at the UTH, Adult Infectious Diseases Centre for at least three months from the time of this study.
b. Who consented or assented and their parents or guardians consented for their child to be included in the study.

3.5.2. Exclusion Criteria

The HIV positive adolescents who were too ill to participate in the study at the time of data collection were excluded from the study.

3.5.3 Sample Size

The sample size was calculated according to Krejcie and Morgan (1970) formula for the limited or finite population.

Formula for calculating sample size for known population was:

$$s = \frac{X^2 NP(1-P)}{d^2(N-1) + X^2 P(1-P)}$$

Where:

- **s** is Sample size
- **X** is the z-statistics for the desired level of confidence; therefore Z = 1.96 for 95% confidence level
- **N** is Total population of HIV positive adolescents at UTH, Adult Infectious Diseases Centre which was 852 patients
- **P** is the margin of error which is 0.5
- **d** is the variance (standard deviation) which is 0.05

$$s = \frac{(1.96)^2 \times 852 \times 0.5(1-0.5)}{(0.05)^2(852-1) + (1.96)^2 \times 0.5(1-0.5)}$$

$$= \frac{3.842 \times 852 \times 0.5(0.5)}{0.0025 \times 851 + 3.841 \times 0.5 \times 0.5}$$

$$= \frac{3269.54 \times 0.25}{4.255 + 0.96025}$$

$$= \frac{817.39}{5.21}$$

$$= 156.88$$

$$= \mathbf{157}$$

With the addition of 10% non-response rate, the final sample size was adjusted as follows: 10/100(157) =15.7 therefore the final sample size was:

157+ 15.7 = **173**

The final sample size was **173**

3.6. Data Collection Tool

The interview schedule modified by the researcher was used to collect data from the eligible study participants. The interview schedule had both open ended and closed ended questions and was categorized into 6 sections (A, B, C, D, E and F). Section A obtained the demographic data to determine the general characteristics of the respondents under study. Section B determined adherence to cART. Section C elicited information on the level of Knowledge to cART treatment and disease process for the HIV positive adolescents to ascertain whether this variable had any effects on adherence to cART. Section D determined the social support for the HIV positive adolescents while section E, determined the religious beliefs that could affect adherence to cART and section F assessed whether stigmatization influenced adherence to cART among HIV positive adolescents. The final section G identified other factors that influenced adherence to cART. Section G also had some recommendations from the HIV positive adolescents and how best non adherence to cART could be abated.

3.6.1.0 Validity

3.6.1.1 Internal validity: Was upheld by ensuring that the tool was brief and precise to ensure maximum respondents participation without getting exhausted and pull out of the study. The tool was checked by the team of expert supervisors before the actual study was conducted. A pilot study was carried out to measure the validity of the questionnaire.

3.6.1.2 External validity: This was upheld by ensuring that the sample size was statistically determined. HIV positive adolescents were included in this study as long as they had met the eligibility criteria.

3.6.2. Reliability

To ensure reliability researcher minimized sources of measurement errors like data collection bias. The biases during data collection were minimized by researcher checking through all the completed questionnaires. The researcher also ensured that conditions such as showing similar standardized personal attributes to all participants such as honesty and support before during and after data collection process were upheld. The physical and psychological environment was made comfortable by ensuring privacy and confidentiality to prevent interruptions.

Reliability of structured questionnaire was tested by pre-testing the instrument before conducting the actual study. A sample with similar characteristics was used to collect data to pre-test the questionnaires. The research assistants were trained to help them understand the questions without distorting the meaning. According to Wood and Haber (2006) once research assistants are trained, it helped in maintenance of consistency, accuracy, stability and homogeneity of data.

3.7. Data Collection Techniques

Data from the respondents was collected through interview schedule using structured questions. Throughout the interview schedule completion privacy and confidentiality was maintained to all study participants. The questions were asked in English or interpreted Chinyanja questionnaire was used to the respondents who could not comprehend the English questions.

The researcher and research assistants ensured that the respondents were made comfortable before commencement of data collection exercise on each day. Respondents were given enough time to understand the questions before answering them. The Data Collection procedure was conducted as follows:

- The researcher and research assistants introduced themselves to the respondents and this was done to make the respondents feel at ease.
- The purpose, risks and benefits of the study were explained to the respondents in order for them to make an informed decision whether or not to participate in the study.
- Confidentiality was assured to the respondents to enable them to participate in the study without fear.
- Consent/Assent was obtained from each respondent before conducting the data collection.
- Questions were read out carefully without cross-examining the respondent and questions which were not understood were interpreted or merely repeated without indicating any direction of the response.

- Questions which were not fully answered by the respondents were rephrased further and clarified to provide clear responses.

All the responses were noted down immediately on the questionnaires to avoid missing out any information.

The interview schedule completion was conducted from Monday to Friday, during working hours from 08:00 to 13:00 hours and took approximately 15 minutes for each respondent.

The researcher/research assistants thanked each respondent at the end for his/her time and participation in the study

3.10 Pre-testing the Instrument

Polit and Hungler (2013) indicated that a researcher should use the pilot study to determine whether the proposed study design is appropriate and to identify any challenges with the proposed study design and it had the following benefits:

- Identification of parts of the instrument that were difficult for the pre-test participants to read and understand or misinterpreted. Hence the pilot study helped the researcher to determine the reliability and validity of the research instrument for this study that was adopted.
- Established the researcher's experience with the respondents (HIV positive adolescents and their guardians in this study).
- Determination of training needs for the research assistants through identification of question sequencing and instrument gaps that were indentified.
- Determining if the instrument measures would yield data with sufficient variability.

The pilot study was conducted at Kabwata Urban Clinic in Lusaka because the site attends to the cases similar to those at AIDC. It consisted of 17 respondents which was a 10% of the actual study sample population who were selected using systematic random sampling method and appropriate adjustments were made to the instrument. This was achieved in consultation with the team of expert research supervisors. These responses from the pilot study were not included in the actual study that was conducted at UTH Adult Infectious Diseases Centre.

3.11 Ethical and Cultural Considerations

The study was conducted in accordance with provisions of the Helsinki declaration (World Medical Association [WMA], (2008) and privacy and confidentiality was safeguarded consistent with guidelines for research involving young people (Mburu et al, 2014).

A continuous evaluation of the research by the supervisor and the co-supervisor, and an ethical clearance (Ref: 006-06-18) to conduct the study was obtained from the University of Zambia School Of Medicine Biomedical Research Ethics Committee and National Health Research Authority of Zambia. Written permissions were obtained from the School of Nursing Sciences, District Health Management Team (DHMT) and The UTHs Management.

Comprehensive information was provided to adolescents, their parents or guardians in English as an official language or commonly spoken Chinyanja language in Lusaka. Study participants signed assent or consent forms depending on the HIV positive adolescents' age. The adolescents between ages 16 and 17 were given the assent form to sign, while those between18 to 19 years signed their own consent forms because the legal age of adulthood in Zambia is 18 (CSO, 2015).

Verbal and written permission from the respondents were sought. The respondents were assured of confidentiality and privacy by explaining to them that only serial numbers were used on the questionnaires and not their names to ensure anonymity. The whole research process was fully explained to all the participants including the nature of the study, procedures, purpose and benefits. The researcher and participant's responsibilities in the study were explained that participants had informed consent to enabled them participate voluntarily in the study. Respondents were not coerced to participate in the study. Those that did not consent to participate were reassured that they would not suffer any consequences of service delivery as a result of not participating.

Completion of the interview schedules was conducted in a private room not accessible to others to ensure privacy. All the questionnaires were kept locked and data analysis was conducted in a private room to ensure confidentiality. There were some temporal emotional or psychological trauma from answering some questions concerning study participant's illness and long life treatment. This was as a result of participants being reminded of the chronic illness of HIV/AIDS and the associated perceived stigmatization. No further discomfort was experienced before during and after the process of data collection. The researcher had a psychosocial counsellor as a measure

to attend to any emotionally or psychologically traumatized participants during the interview considering the nature of the condition.

CHAPTER FOUR: DATA ANALYSIS AND PRESENTATION OF FINDINGS

4.1 Introduction

This chapter presents data collected from 173 HIV positive adolescents on cART aged between 16 and 19 years from Adult Infectious Diseases Center, Lusaka, Zambia it describes how the processing and analysis of the data was performed.

4.2. Data Processing and Analysis

Following data collection, the questionnaires were sorted out and edited for internal consistence, completeness, legibility and accuracy. Completed questionnaires were kept in lockable cupboard while soft copies were kept on a laptop with a password known by the researcher only. Responses from closed ended questions were assigned numerical codes for easy entry and analysis using the SPSS software computer package version 20. Open ended questions in the questionnaires were processed by reading through the data in its entirety to identify and group answers that belonged to the same category. This process is known as categorization (Polit et al, 2012). The categories were then assigned numerical codes which were entered and analyzed.

Data analysis involved descriptive and inferential statistics consistent with Moxham (2012). Descriptive statistics describe, synthesize, show data patterns and trends of variables under study (Moxham, 2012) whereas inferential statistics permit the investigator to infer whether relationships noted in a sample might be generalized to a larger population (Polit and Hungler, 2013). To analyze variables statistically, operationalization into measurable form using numbers or scores was used according to Borbasi and Jackson (2012).

The variables under study were assessed on how each independent variable predicted the dependent variable and how these were important in determining adherence to cART among the HIV positive adolescents. Pearson's Chi square and fisher's exact statistical tests were used to determine the association between dependent (adherence to cART) and independent variables (knowledge of HIV and disease progression, social support, stigmatization and cultural beliefs). The fisher's exact test was used where the criteria for using the Pearson's chi square was not met. The binary logistic regression test was used to come up with the true predictors and to adjust confounders of adherence to cART among HIV positive adolescents.

The cut off point for statistical significance was set at 5%. Therefore, p values equal or less than 0.05 were considered to be statistically significant thereby rejecting the null hypothesis. If a probability result was statistically significant the p value of <0.05 was used to indicate that results were not by chance and was significant and important (Polit and Hungler, 2013).

4.3 Presentation of Data

The findings of this study were presented according to the sequence of questions and sections of the questionnaires. Numerical data were presented in two forms, firstly as raw figures and percentages, secondly more visually in form of bar charts, pie charts, and frequency and cross tabulations tables (Burns and Grove, 2009) for easy understanding.

Section A represents the demographic characteristics of the respondents, section B represent the respondents' pattern of adherence to cART, while knowledge on HIV and disease progression was shown in section C. Section D shows the respondents' perceived social support system and sections E and F show Religious beliefs and Stigmatization respectively. The cross tabulations in section G represent the relationship that exist between variables. The cross tabulations are helpful in showing relationships between variables (Polit and Hungler, 2013).

4.3.1 Social Demographic data

This unit presents the social demographic characteristics of the study respondents.

Table 3: Social Demographic Data (n=173)

	Frequency	**Percentage**
Sex		
Male	85	49.1
Female	88	50.9
Total	**173**	**100**
Age		
16 – 17	92	53.2
18 – 19	81	46.8
Total	**173**	**100**
Level of education		
Primary	63	36.4
Secondary	91	52.6
Tertiary	16	9.2
None	3	1.8
Total	**173**	**100**
Residence		
Friends	**1**	0.6
Family	172	99.4
Total	**173**	**100**
Parentage Status		
Both parents Alive	66	38.1
Father alive	31	17.9
Mother alive	43	24.9
Both Parents Died	33	19.1
Total	**173**	**100**
Caregiver		
Biological parent(s)	115	66.5
Grandparents	23	13.3
Uncle/Aunty	26	15
Siblings	9	5.2
Total	**173**	**100**

The current study found a slight gender imbalance where almost half 49.1% (85) of the study respondents were males. HIV prevalence and AIDS-related mortality in male adolescents compared to females has been relatively higher which may be related to the lower proportion of males who receive ART (UNAIDS, 2015). Slightly above half 53.2% (92) of the respondents were within the age group range of 16 – 17 years. Slightly above half 52.6% (91) of the respondents had attained secondary school education. These results were expected because 95% of the respondents in the current study had adequate social support (Figure 7). The majority 99.4% (172) of the respondents were living with their family i.e. biological parents, grandparents and uncle or aunty. Above one third 38.1% (66) respondents had both biological parents still alive. The majority of the respondents had either their father 24.9% (43) or mother 17.9% (31) dead and 19.1% (33) had reported that both of their parents had died (Table 3).

4.3.2: Adherence assessment

The findings pertaining to adherence assessment of the study respondents has been presented under this unit.

Table 4: cART Adherence (n = 173)

Ever forgotten to taking medication	**Frequency**	**Percent**
Yes	64	37.0
No	109	63.0
Total	**173**	**100.0**
Find it difficult taking medication		
Yes	26	15.0
No	147	85.0
Total	**173**	**100.0**
Sometimes stop your medication		
Yes	7	4.0
No	166	96.0
Total	**173**	**100.0**
Stops taking medication when feels worse		
Yes	5	2.9
No	168	97.1
Total	**173**	**100.0**

Most respondents 63% (109) reported that they had never forgotten to take their cART while 37% (64) did forgot taking their medications as prescribed. The majority of the respondents 85% (147) were found not to have difficulties in taking their cART and only 15% (26) reported difficulties in taking their drugs. Few respondents 4% (7) reported that they sometimes stop taking their cART when they felt much better. The majority 96% (166) continued taking their cART even when they had an improved condition. Very few 2.9% (5) respondents were reported that they stop taking their cART when they felt very sick (Table 4).

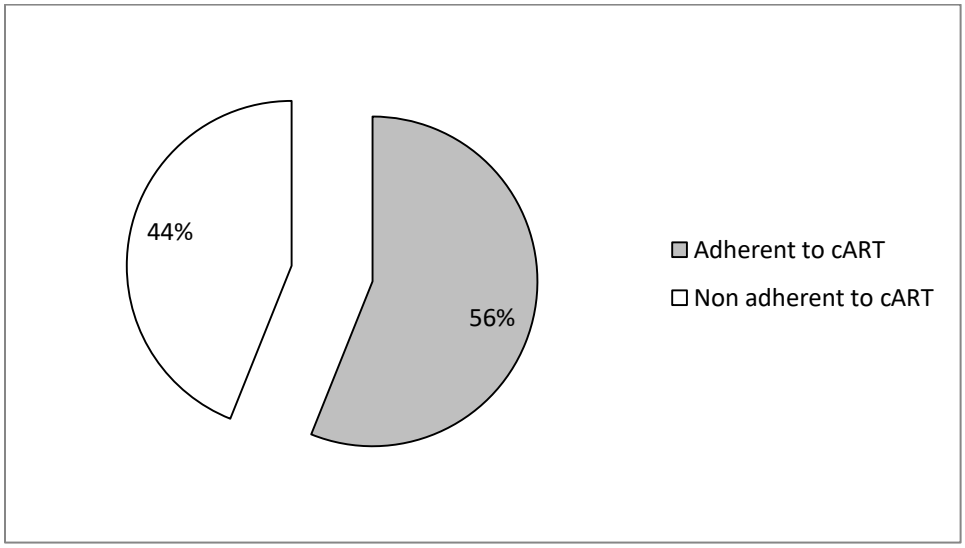

Figure 3: Adherence to cART assessment (n=173)

Generally in this study, 44% (76) of the respondents were found to be non adherent to cART (Figure 3).

4.3.3 Knowledge about HIV and disease Progression

This unit presents data about the study respondents' knowledge about HIV and the disease progression.

Nearly all 99.6% (172) respondents knew that they were living with HIV.

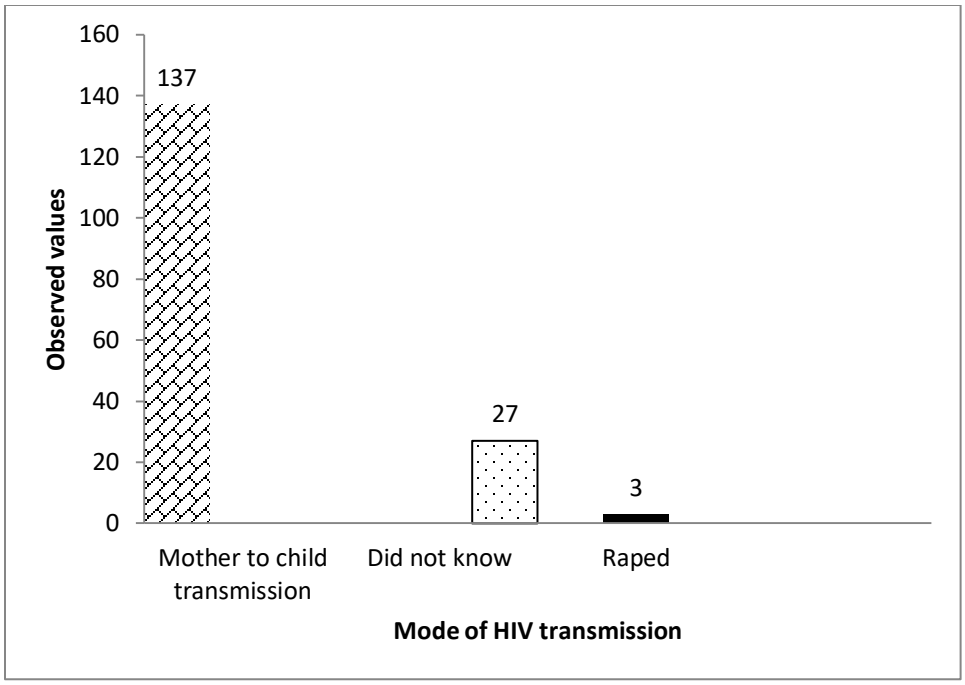

Figure 4 Mode of HIV transmission (n=173)

The majority 79.2% (137) of the respondents got the HIV through Mother to child transmission, while 15.6% (27) did not know how they got the infection. The 1.7% (3) of the respondents got the HIV infection from being raped in their home set ups.

Table 5: whether respondents understood why they were taking ARV (n=173)

Understand reasons why you are taking ARV	**Frequency**	**Percent**
Not at all	6	3.5
Not very sure	36	20.8
Very much	131	75.7
Total	**173**	**100.0**

A fraction above three quarters of the respondents 75.7% (131) showed good understanding of the reason they were taking the cART. A small percentage 3.5% (6) did not know the reason for taking the cART and 20.8% (36) were not very sure of the correct reasons.

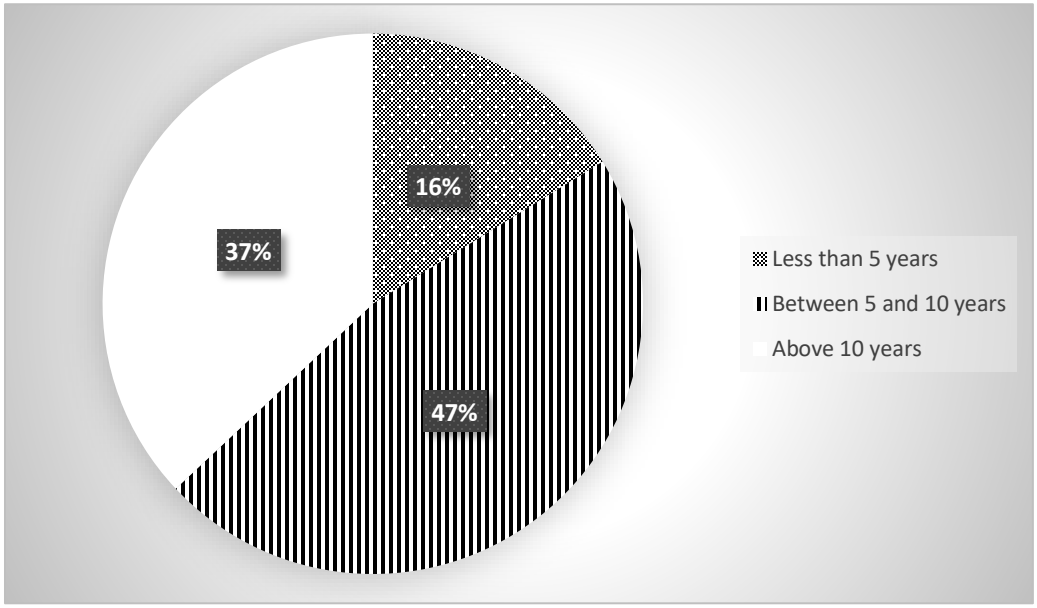

Figure 5: Duration of taking cART (n=173)

Slightly below half 47% (81) of the respondents had been on cART between 5 and 10 years and 37% (64) for longer than 10 year.

Table 6: Whether respondents know which cART they were started with (n=173)

cART you were started with	Frequency	Percent
NNRTI Based	48	27.7
PI Based	6	3.5
Mono/Dual therapy	3	1.7
I don't know	116	67.1
Total	**173**	**100.0**

Most respondents 67% (116) were found that they did not know the cART drugs that they were started with. The 27.7% (48) of the respondents know that they were started with NNRTI based regime.

Table 7: Whether Respondents experienced cART side effects; know their recent CD4 cell count and viral load (n=173)

Experienced drugs side effects	**Frequency**	**Percent**
No	141	81.5
Yes	32	18.5
Total	**173**	**100.0**
Knows recent CD4 cell count		
Yes	40	23.1
No	133	76.9
Total	**173**	**100.0**
Knows recent viral load measure		
Yes	35	20.2
No	138	79.8
Total	**173**	**100.0**
OIs while on cART		
Yes	26	15.0
No	147	85.0
Total	**173**	**100.0**

The 18.5% (141) of the respondents reported experiencing some side effects of cART. The larger percentage 76.9% (133) respondents did not know their most recent CD4 cell level. More than three quarters 79.8% (138) of the respondents did not know their recent viral load measure. In this study 15% (26) respondents know that they had suffered from an opportunistic infection.

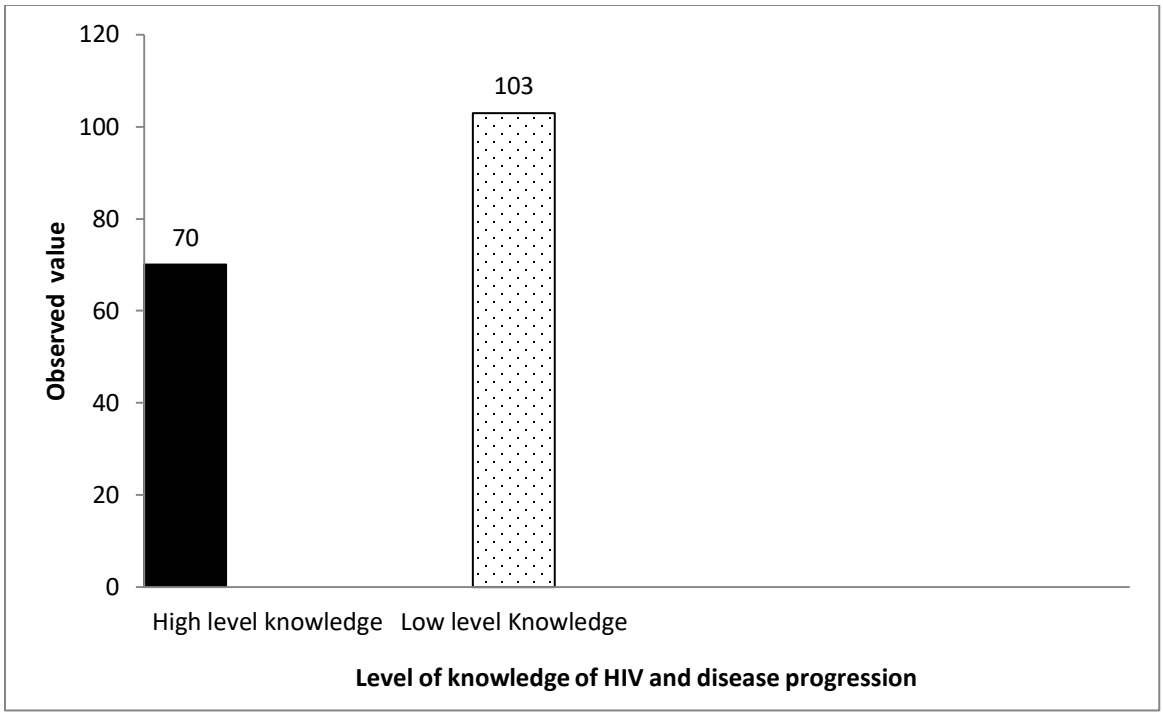

Figure 6: Respondents Level of Knowledge about HIV and disease Progression (n=173)

Most respondents 59.5% (103) were found to have low level knowledge about HIV and disease progression.

4.3.4: The social support

In this unit the social support of the respondents has been presented.

Table 8: Accessibility to healthcare (n=173)

Accessibility to healthcare	**Frequency**	**Percent**
Very easy	122	70.5
Sometimes easy sometimes difficult	48	27.7
Very difficult	3	1.7
Total	**173**	**100.0**

Nearly three quarters 70% (122) of the respondents had easy access to the healthcare facility for their HIV treatment and care. The 27.7% (48) respondents reported finding it difficult and easy sometimes to access the care.

Table 9: Drugs collection when respondents unable by themselves (n=173)

Who collects drugs on behalf of respondents	**Frequency**	**Percent**
Family member	100	57.8
Friends	2	1.2
Nobody	71	41.0
Total	**173**	**100.0**

When respondents are unable to go to the hospital to collect their drugs it was reported that 57.8% (100) family members went on their behalf. Unfortunately 41% (71) respondents had nobody to go to the hospital to collect their cART.

Table 10: Whether respondents felt attending appointments interfered with their life (n=173)

Appointments interfere with life	Frequency	Percent
Not at all	108	62.4
Sometimes	51	29.5
Very much	14	8.1
Total	**173**	**100.0**

Some respondents 29.5% (51) reported that they get interfered with their lives by attending to the hospital appointments.

Table 11: Follow up missed appointments by healthcare provider (n=173)

Healthcare providers follow up missed appointments	Frequency	Percent
No	139	80.4
Yes by phone call or SMS	34	19.6
Total	**173**	**100.0**

The majority 80.3% (139) reported that when they missed an appointment, they did not receive any follow up to establish the reason by the healthcare providers.

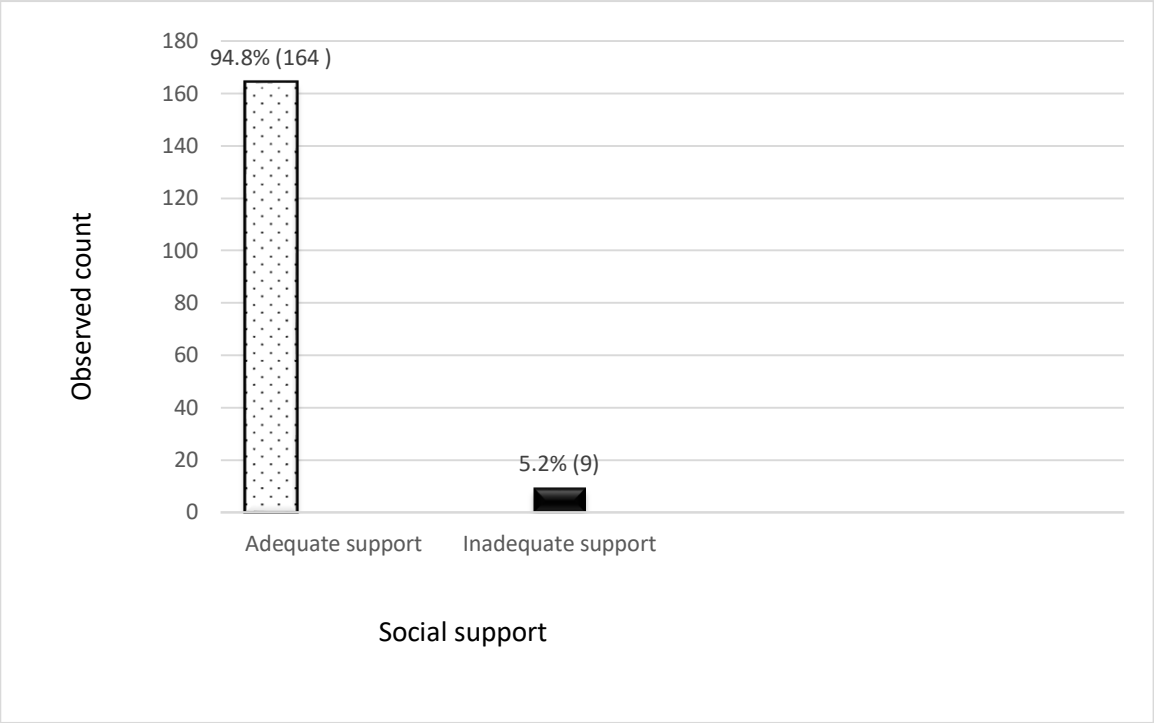

Figure 7: showing the Level of Social Support for HIV Positive Adolescents (n=173)

The majority of the respondents 94.8% (164) reported to have adequate social support and only 5.2% (9) had inadequate social support.

4.3.5: Religious beliefs

The study respondents' religious beliefs that could lead to non-adherence to cART have been presented in this unit were all the respondents 100% (173) interviewed were from Christian community.

Table 12: Religious Beliefs by respondents that prayers and anointing oil could heal HIV/AIDS (n=173)

Belief that Prayer and anointing oil could heal HIV/AIDS	**Frequency**	**Percent**
Yes	90	52.1
No	67	38.7
Not sure	16	9.2
Total	**173**	**100.0**

Out of 173 respondents 52.1% (90) believed that prayers and anointing oil could cure HIV/AIDS.

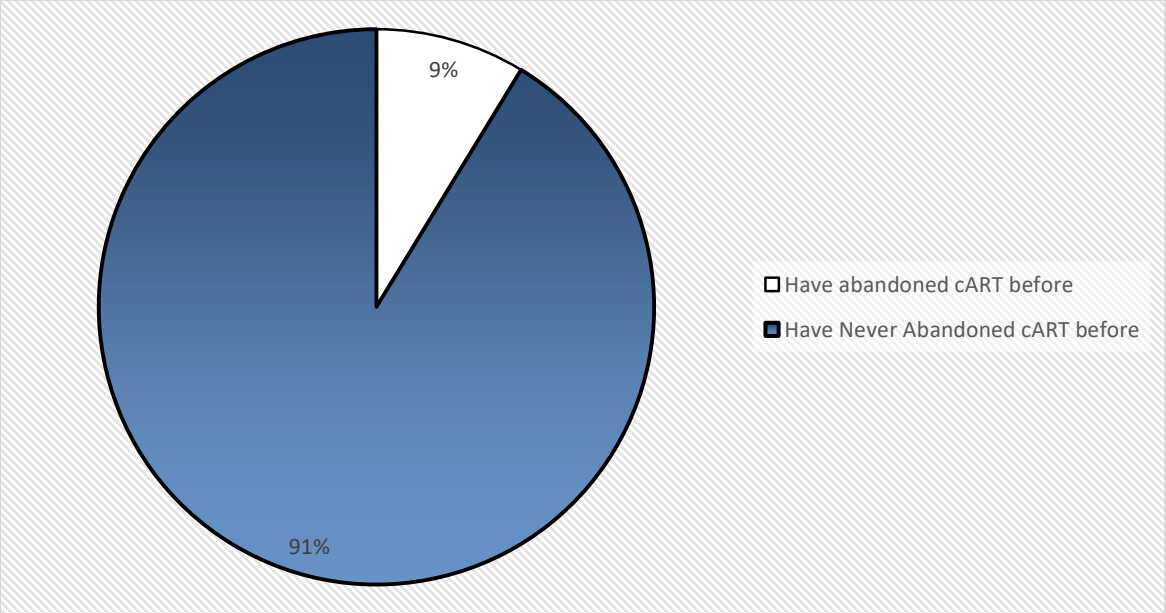

Figure 8: Whether respondents had abandoned treatment before in preference to prayers at some point (n=172)

Some HIV positive adolescents 9 % (15) reported that they had at one point abandoned cART in preference of prayers. The larger percentage 91% (157) of the respondents have never abandoned cART.

Table 13: Whether respondents at any point had abandoned cART to take traditional medicines to try and cure the illness (n=173)

Took traditional medicine to try and cure HIV	**Frequency**	**Percent**
Yes	4	2.3
No	169	97.7
Total	**173**	**100.0**

A small percentage of respondents 2.3% (4) reported to have at some point abandoned cART in preference to traditional medicines to try and cure the disease.

4.3.6: Stigmatization

In this unit level of stigmatization has been assessed and presented for the study respondents

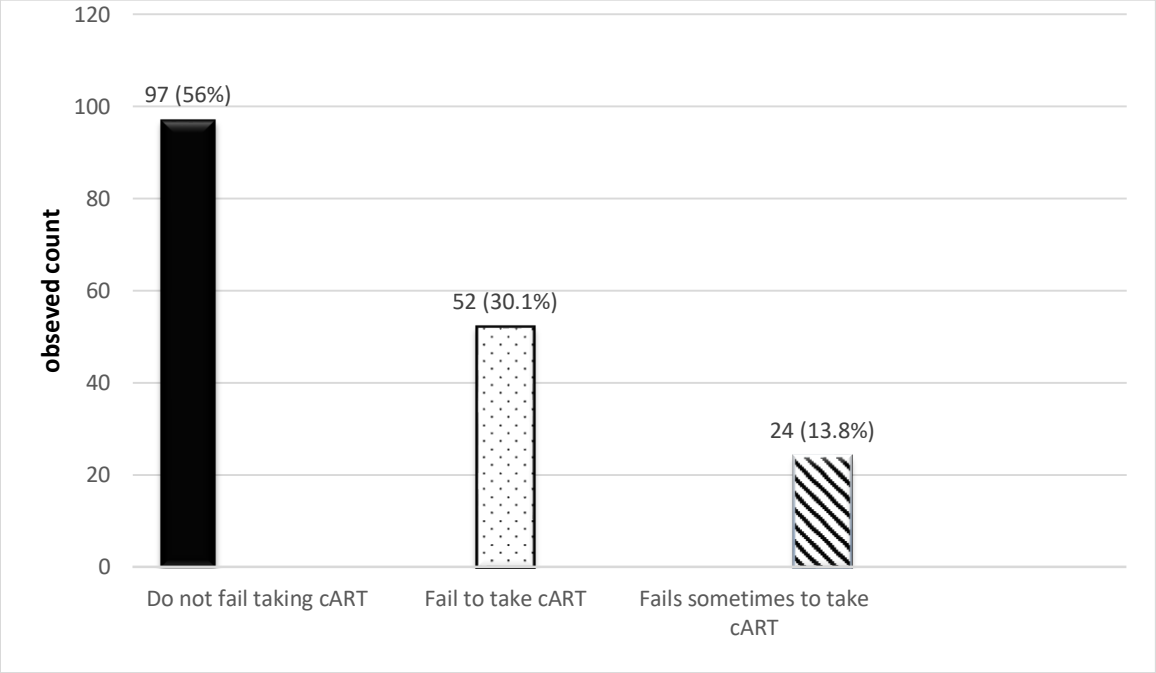

Figure 9: Failure to take medication by respondents when friends, teachers, or other people are around (n=173)

Nearly one third 30.1% (52) of the respondents fail to take their cART because of friends, teachers or other people being around. The other 13.8% (24) however sometimes reported failing taking their medications when friends or other people are around.

Table 14: Whether respondents felt stigmatized in community and uncomfortable collecting medications from the clinic/Hospital (n=173)

Felt uncomfortable collecting medication from the clinic/Hospital	**Frequency**	**Percent**
Yes	15	8.7
No	128	74.0
Sometimes	30	17.3
Total	**173**	**100.0**
Felt there was stigmatization towards people living with HIV in community		
Not at all	63	36.4
Sometimes	72	41.6
Very much	38	22.0
Total	**173**	**100.0**

A few participants 8.7% (15) felt uncomfortable going to collect their medications from the clinic/hospital and 17.3% (30) were uncomfortable sometimes.

The 41.6% (72) of the respondents felt that there was sometimes stigma towards the people living with HIV in the community. The 22% (38) respondents strongly felt that there was stigmatization.

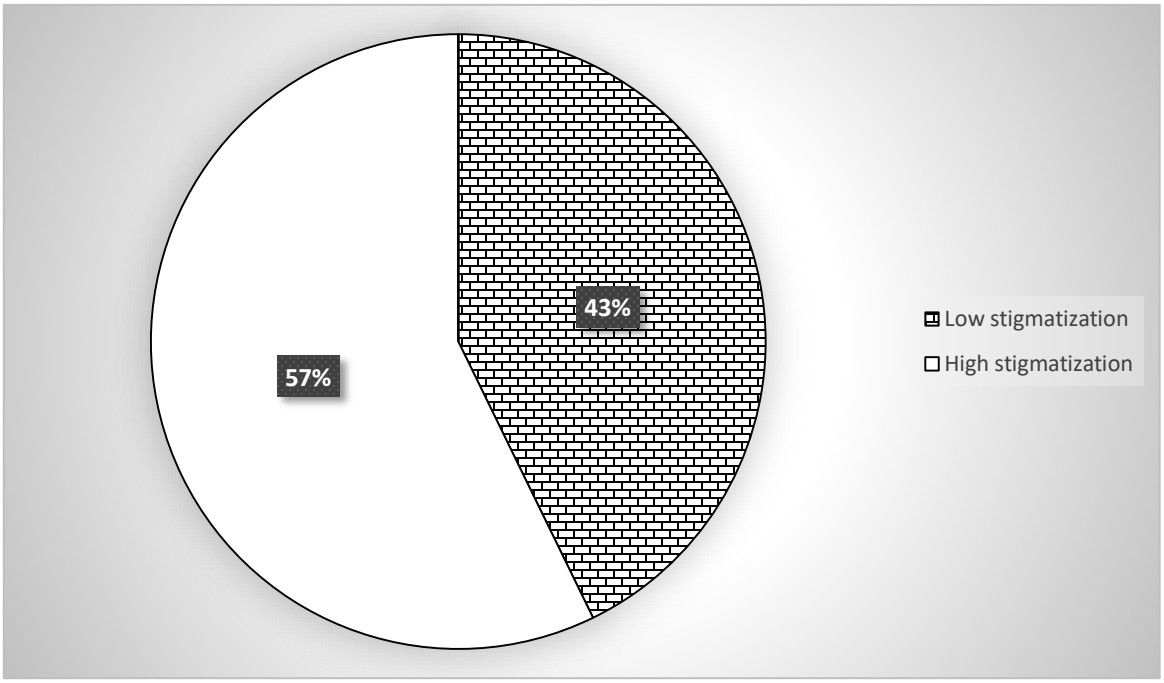

Figure 10: Level of stigmatization (n=173)

Generally 57.2% (99) of the respondents reported high level of stigmatization experience.

4.3.7: Relationships among study variables

The relationship of the dependent variable and independent variables has been presented in this unit.

4.3.7.1: Association between adherence to cART and social demographic variables

Table 15: Association between adherence to cART and the social demographic variables (n = 173)

	Adherence to cART			
Characteristic	**Adherence No (%)**	**Non adherence No (%)**	**Total**	**P values**
Gender				
Male	47(54.7%)	39(45.3%)	86(100%)	
Female	50(57.5%)	37(42.5%)	87(100%)	
Total	97(56.1%)	76(43.9%)	173(100%)	0.760
Age				
16 – 17	49(53.3%)	43(46.7%)	92(100%)	
18 – 19	48(59.3%)	33(40.7%)	81(100%)	
Total	97(56.1%)	76(43.9%)	173(100%)	0.428
Level of education				
Primary	33(53.2%)	29(46.8%)	62(100%)	
Secondary	52(56.5%)	40(43.5%)	92(100%)	
Tertiary	10(62.5%)	6(37.5%)	16(100%)	
None	2(66.7%)	1(33.3%)	3(100%)	
Total	97(56.1%)	76(43.9%)	173(100%)	0.893

Of 97 respondents who were found to be adherent to cART 48% (47) were females and 52% (50) were males. Among the respondents that were found to be non adherent to cART (76) slightly above half 51% (39) were males. It was found that gender was independent of adherence to cART (*p-value of 0.760*).

The majority of the participants 57% (43) of those where non adherent were aged between 16 and 17 years old while those age between 18 and 19 years 43% (33) were reported to be non adherent to cART. Adherence to cART was found to be independent (*p-value 0.428*) of the age of the study

respondents. The 54% (52) of the respondents found to be adherent were at secondary school education level equally of those that were non adherent 53% (40) were at secondary school level. When adherence to cART was associated with the level of education there was no significant association (*p-value 0.893*).

Table 16: Association between adherence to cART and the social demographical variables (n = 173)

	Adherence to cART			
Parameter	**Adherent**	**Non adherent**	**Total**	**P values**
Caregiver				
Biological parent(s)	64(55.7%)	51(44.3%)	115(100%)	
Grandparents	14(60.9%)	9(39.1%)	23(100%)	
Uncle/Aunty	13(50%)	13(50%)	26(100%)	
Siblings	6(66.7%)	3(33.3%)	9(100%)	
Total	97(56.1%)	76(43.9%)	173(100%)	0.796
Parentage Status				
Both parents Alive	35(53.8%)	30(46.2%)	65(100%)	
Father Alive	16(51.6%)	15(48.4%)	31(100%)	
Mother Alive	25(58.1%)	18(41.9%)	43(100%)	
Both Parents Died	21(61.8%)	13(38.2%)	34(100%)	
Total	97(56.1%)	76(43.9%)	173(100%)	0.824

Respondents whose both care givers were biological parents 66% (64) were adherent to their cART compared to 14% (14) for those whose caregivers were grandparents. The 67% (51) respondents whose caregivers were biological parents were non adherent to cART compared to 12% (9) of the respondents whose caregivers were grandparents. However when adherence to cART was associated with type of caregiver, there was no significant finding (*p-value 0.796*). When the respondents' both parents were alive adherence to cART was reported to be 36% (35) but when both parents had died 22% (21) were adherent to cART. When both parents had died 39% (30) respondents were reported non adherent to cART while when both parents had died 17% (13) were

non adherent to cART. When the father was alive it was found that 20% (15) respondents were non adherent where as 24% (18) were non adherent when their mother was alive. When the father was alive it was found that 16% (15) respondents were adherent where as 26% (25) were adherent when the mother was alive. When adherence to cART was associated with parentage status of the respondent, there was no significant finding (*p-value 0.824*).

4.3.7.2: Association between adherence to cART and Understanding reason for taking cART.

Table 17: Association between adherence to cART and understanding reason for taking cART (n = 173)

	Adherence to cART			
Parameter	**Adherent**	**Non adherent**	**Total**	**P-Value**
Understood reason for taking cART				
Not at all	15(35.7)	27(64.3%)	42(100%)	
Very much	82(62.6%)	49(37.4%)	131(100%)	
Total	**97(56.1%)**	**76(43.9%)**	**173(100%)**	**0.006**
cART Side effects				
No	84(59.6%)	57(40.4%)	141(100%)	
Yes	13(40.6%)	19(59.4%)	32(100%)	
Total	**97(56.1%)**	**76(43.9%)**	**173(100%)**	**0.05**
Reminded taking cART				
Never	43(72.9%)	16(27.1%)	59(100%)	
Always	54(47.9%)	60(52.1%)	114(100%)	
Total	**97(56.1%)**	**76(43.9%)**	**173(100%)**	**0.006**

Among the respondents who were adherent to cART 85% (82) understood very much the reason for taking cART while only 15% (15) who did not understand the reason were reported to adherent. Understanding the reason why the respondents were taking their cART was found to be strongly dependent (*p-value 0.006*) with adherence to cART. The respondents 86% (84) of the respondents

who did not experience cART side effects were found to be adherent to their drugs. Despite experience cART side effects 14% (13) respondents were reported to be adherent to cART. And quarter 25% (19) of the respondents who were reported to be non adherent to cART experienced some side effects of the drugs. There was a relationship between experiencing cART related side effects and adherence to cART (*p-value 0.05*).

This study found that 72.9% (43) of the respondents who were never remained to take their cART had good adherence and 47.9% (54) of those that were always reminded were reported adherent. The respondents who were always reminded to take their cART 52.1% (60) were reported to be non adherent while 40.4% (57) who were never reminded were non adherent to cART. Being reminded to take cART was dependent of adherence to cART (*p-value 0.006*).

Table 18: Association between adherence to cART and the level of knowledge about HIV and disease progression (n = 173)

	Adherence to cART			
Parameter	**Adherent**	**Non adherent**	**Total**	**P-Value**
Knowledge level				
High	41(58.6%)	29(41.4%)	70(100.0%)	
Low	56(54.4%)	47(45.6%)	103(100.0%)	
Total	97(56.1%)	76(43.9%)	173(100.0%)	**0.585**

This study established that 58% (56) of the respondents who were adherent to cART had low level knowledge. Among those that were reported to be non adherent, 62% (47) had low knowledge of HIV and disease progression. There was no significant association between adherence to cART and the level of knowledge *(p-value was 0.585).*

4.3.7.3: Association between adherence to cART and social support

Table 19: The social support for the respondents

	Adherence to cART			
Parameter	**Adherent**	**Non adherent**	**Total**	**P-Value**
Social support level				
Adequate	94(57.3%)	70(42.7%)	164(100%)	
Inadequate	3(33.3%)	6(66.7%)	9(100%)	
Total	97(56.1%)	76(43.9%)	**173(100%)**	**0.158**

The report indicates that 97% (94) respondents among those that were adherent to cART had adequate social support. It was further reported that 92% (70) of those who where non adherent had adequate social support. When social support was associated with adherence to cART among HIV positive adolescents it was found that there was no association (*p-value 0.158*). Overly about 95% (164) of the participants had demonstrated adequate social support.

4.3.7.4: Association between adherence to cART and religious beliefs

Table 20: Religious beliefs association with adherence to cART

	Adherence to cART			
Parameter	**Adherent**	**Non adherent**	**Total**	**P-Value**
Religious belief				
Positive	86(55.8%)	68(44.2%)	154(100%)	
Negative	11(57.9%)	8(42.1%)	19(100%)	
Total	97(56.1%)	76(43.9%)	173(100%)	**0.865**

The majority 55.8% (86) of the participants who were found to have positive religious belief were adherent to cART in this study. Despite having positive religious beliefs 44.2% (68) were non adherent to cART. However, adherence to cART was found to independent of religious belief (*p-value of 0.865*).

4.3.7.5: Association between adherence to cART and Stigmatization among respondents

Table 21: Association between adherence to cART and Stigmatization among respondents

	Adherence to cART			
Parameter	**Adherent**	**Non adherent**	**Total**	**P-Value**
Stigmatization				
High	51(51.5%)	48(48.5%)	99(100%)	
Low	46(62.2%)	28(37.8%)	74(100%)	
Total	97(56.1%)	76(43.9%)	173(100%)	**0.205**

Among respondents that were non adherent to cART 63% (48) had high level of stigmatization and 37% (28) had low level stigmatization. Respondents who were adherent to cART 53% (51) had high level of stigmatization. The association of adherence to cART and stigma was found to be independent (*p-value of 0.205*).

4.3.7.6: Association between adherence to cART and Stigmatization among respondents

Table 22: Association between adherence to cART and Being satisfied with HIV care services

	Adherence to cART			
Parameter	**Adherent**	**Non adherent**	**Total**	**P-Value**
Being satisfied with HIV services				
Not at all	6(31.6%)	13(68.4%)	19(100%)	
Very Much	90(58.8%)	63(41.2%)	153(100%)	
Total	96(55.8%)	76(44.2%)	172(100%)	**0.04**

The respondent 94% (90) who had reported being very much satisfied with HIV services were adherent to cART. While 6% (6) of those that were adherent to cART reported not being satisfied at all with the services. Being satisfied with HIV care services was found to be strongly dependent with adherence to cART (*p value 0.04*).

4.3.8 Binary logistic regression analysis

This unit presents how data was further analyzed using the binary logistic regression.

Table 23: Binary logistic regression output-Variables in the equation

Variable	p – value	Odds Ratio	95% C.I. for Odds Ratio (1.0 ref)	
			Lower	Upper
Knowledge(1)				
High	0.375	0.723	0.353	1.481
Low		0.839	0.456	1.557
Social support(1)				
Adequate	0.369	1.993	0.442	8.983
Inadequate		0.158	0.341	1.346
Religious Beliefs(1)				
Positive	0.818	0.885	0.311	2.514
Negative		0.029	0.452	1.232
Stigma(1)				
High	0.228	0.644	0.315	1.316
Low		0.205	0.562	1.785
Reminding	0.016			
Reminding(1)	0.004	0.315	0.144	0.691
Reminding(2)	0.27	0.505	0.15	1.698
Side Effects(1)	0.047	0.412	0.172	0.987
Understand	0.011			
Having Understanding(1)	0.578	1.935	0.189	19.83
No Understanding(2)	0.12	5.982	0.629	56.895
Constant	0.769	0.627		

In order to test the impact of the predictor variables (knowledge of HIV and disease progression, social support, religious beliefs, stigmatization, Being reminded to take the cART drugs, side

effects of drugs and understanding of reason for taking cART) on the outcome variable (adherence to cART), a binary logistic regression was done.

The regression model was statistically significant as a whole ($X^2 = 26.621$, $p = 0.002$) and could account for 19.1%, variation in the outcome variable, making it a weak model. In terms of prediction power, the model could predict non adherence with 59.2% accuracy and adherence with an accuracy of 75.3%. As a whole, the model had an overall prediction accuracy of 68.2%.

Further data analysis with the binary logistic regression found that, inside the equation changes in knowledge levels from low to high, social support from inadequate to adequate, religious beliefs from negative to positive, and stigma from low to high did not contribute significantly to the model. Being reminded to take cART variable as a whole was impacted significantly on the model ($p = 0.016$), and changes in reminders to take treatment from never to sometimes contributed significantly but reduced the odds of adherence by 68.5% ($p = 0.004$, odds ratio = 0.315). While changes in reminder from sometimes to always reduced the odds of adherence by 40.5% though the impact was not statistically significant ($p = 0.27$, odds ratio = 0.505).

The overall impact of the understanding variable was statistically significant ($p = 0.011$). Changes in understanding from not at all to sometimes raised the odds of adherence by 93.5% but did not impact significantly on the model ($p = 0.578$, odds ratio = 1.935) while changes from sometimes to very much raised the odds of adherence by 498.2% although the impact was not statistically significant ($p = 0.12$, odds ratio = 5.982). Changes in the experience of side effects of the drugs from no to yes contributed significantly to the model and reduced the odds of adherence to 41.2% ($p = 0.047$, odds ratio = 0.412).

CHAPTER FIVE: DISCUSSION OF FINDINGS

5.1 Introduction

This chapter discusses the study findings obtained and the outcomes of association of dependent (adherence to cART) and independent (knowledge of HIV and disease progression, social support, stigmatization and cultural beliefs) variables. The discussion follows the application of the constructs which underpinned the study.

5.2 Socio-demographic characteristics of the study sample

The social demographic characteristics showed that 50.9% (88) of the respondents interviewed were female. The slightly high proportion of female respondents may be due to older male partners infecting them in contexts of poverty, manipulation and exploitation without condom use. To support this view the current study found that 1.7% (3) of the HIV positive adolescents respondents got the infection from being raped by males in their home set ups. Men in such relationships often have multiple sexual partners and acquire sexually transmitted infections, which they pass on to adolescent females (UNICEF, 2012). Parienti (2014) reported that high female rates may be related to unprotected heterosexual relations with multiple partners. An additional factor contributing to the sex imbalance in adolescent HIV prevalence may be the higher risk of AIDS-related mortality in male adolescents compared to females, which may be related to the lower proportion of males who receive cART (UNAIDS, 2015).

Similar to the current study, Idele et al (2014) reported higher rates of HIV among females than males in sub-Saharan Africa. According to UNICEF (2014) reports, females aged 15 to 17 years in the sub-Saharan region have up to four times higher prevalence rates of HIV reported than among their male counterparts. The similar high prevalence among females may be due to similar inter-cultural belief systems and practices which promote HIV transmission on the girl child. The practices could include high cases of early marriages to female adolescents and adult HIV infected practicing sexual intercourse ritual with a minor girl child to try and cure the infection (CSO, 2015).

Contrary to findings in the current study, the highest HIV prevalence rate in the United States and parts of Europe was reported among males (UNAIDS, 2013). In the developed settings the prevalence among male adolescents could be higher because of injectable illicit drugs abuse using

same needle by several group members. The use of the same needle among several adolescents within the same gang, could contribute to high HIV rates among males (CDC, 2014).

The study also revealed that more than half (53.2% [92]) of the respondents were within the age group 16 – 17 years. This statistics suggest that most of the perinetally infected adolescents are now living longer attributed to improved HIV/AIDS care services. Most 52.6% (91) of the respondents had attained secondary school education. This is contrary to the beliefs that HIV diagnosis is a death sentence and there was no need to pursue career or educational goals (Baumgartner, 2012). Kanabkaew et al (2017) observed that with the advances in effectiveness and availability cART, HIV infected children are now surviving to adolescence and emerging as a new group in the global HIV/AIDS pandemic. Kanabkaew et al (2017) observed that despite the fact that HIV positive adolescents find it a challenge living with the HIV, they have remained positive and focused with their education.

The majority of the respondents had either their father 24.9% (43) or mother 17.9% (31) dead and 19.1% (33) had both their parents dead. This could mean that most respondents were more likely to have housing instability and this affects consistence in clinical monitoring visits and to obtain cART medications. In the current study it was reported that respondents whose care givers were biological parents (66% [64]) were adherent to their cART compared to those whose caregivers were grandparents. Parents are the best source of emotional and physical support to the children hence the higher adherence to cART recorded among those who had their both parents alive. However, there is a slight difference when the father was alive, 20% (25) and when the mother was alive, 26% (25). This difference could be attributed to the differences in cultural inclined gender roles where a man must be away from home to fetch for the family while a woman should take care of the children at home. As a result more women seem to be more inclined to caring of the sick children than the male parents.

5.3 Adherence to cART by the respondents

Respondents in the current study (44% [76]) were found to be non adherent to their prescribed cART. It must be emphasized that according to Boussari et al (2015) adherence to cART is critical for successful viral suppression because non adherence could lead to an increase in HIV viremia, risk of treatment failure, and accumulating resistance mutations. The 44% non adherence rate is

very alarming and pauses as a threat to the maintenance of future cART regimen among HIV positive adolescents due to possible occurrences of related drug resistance and virologic failure.

Similar to the current study, Kanabkaew et al (2017) in Thailand also found even slightly higher (48.4%) suboptimal adherence to cART among adolescents. Despite difference in geographical locations Nglazi (2012) noted that there could be some similar characteristics which exist and affecting the pattern of cART adherence among adolescents. It could be said that non adherence to cART is becoming a global phenomenon and collective strategic efforts need to be developed to prevent the risk of development of treatment failure. Several studies in sub-Saharan Africa have also reported poor adherence behavior among adolescents which is of significant concern given the limited cART options available and the risk of drug resistance (Muri et al, 2017 Nglazi, 2012). Muri et al (2017) perceived non adherence to cART as an emerging public health concern.

Among the respondents that were found to be non adherent to cART, slightly above half 51% (39) were males. These findings in the current study confirms the growing body of evidence indicating that male adolescents face challenges in accessing HIV services more often than their female counterparts. The males also experience worse treatment outcomes, including high mortality according to Dybul et al (2013). With these challenges among male adolescents it is likely that they may not adhere to their cART. Elsewhere Lowenthal et al (2013) also reported sex-specific differences outcomes that male adolescents had worse adherence compared to their female counterparts. Globally more emphasis has been placed on protection of the girl child and as a result the male child seems to be disadvantaged much more in health related matters (Adejumo, 2015). However, it was found that gender was independent of adherence to cART. This could be attributed to the fact that the pathogenesis of HIV is similar despite the person's gender.

The current study found that majority of the respondents 57% (43) who were non adherent were aged between 16 and 17 years old. This coincides with the age when adolescents are transitioned from pediatrics to adults HIV care. The higher non adherence to cART occurring during this period could be attributed to some challenges associated with implementation of transitioning process of care. Adejumo (2015) observed that transitioning of care from pediatrics to adult should be a gradual process according to the maturity of the adolescents with evidence of psychological stability and readiness of independent care. A similar study in Zambia by Katayamoyo et al (2016) contrary to the current study concluded that there was suboptimal adherence to cART mainly due

to increase in age as the main contributing factor. This could have been that as adolescents increase in age, they are expected to take up more gender roles and responsibilities in society. According to Evans et al (2013) the successful fulfillment of new gender roles and responsibilities could come with challenges that may disrupt the routine daily activities including medication timings.

Adherence to cART was found to be independent of the age of the adolescent in the current study. The adolescents' age did not significantly influence adherence and there was a minimal difference in the pattern of adherence to cART between older and younger adolescents. It can be argued that despite the age of the adolescents they experience similar influences of adherence to cART. Although some studies have shown high rates of cART adherence among HIV-infected adolescents, a lower rate of adherence among HIV-infected adolescents has been reported more often, and expectations have been that adherence will diminish over time (Evans et al, 2013; Kanabkaew et al, 2017). More cohort studies need to be conducted to identify the non enhancers of adherence to cART.

5.4 Knowledge of HIV and disease progression of the respondents

In the current study, majority (59.5% [10]) of the respondents were found to have low level knowledge about HIV and disease progression. Earlier CDC (2014) had highlighted that low level of knowledge among adolescents could be due to limited access to health information and little sources of information about HIV and disease progression. The health information could easily be shared in adolescents- friendly health corners which according to Zambian consolidated treatment and prevention guidelines (2016) are very limited in most health care centers. Limited adolescent-friendly health corners may therefore contribute to low level of knowledge about HIV and disease progression. Efforts to improve knowledge and maintain adherence to cART, have been noted where adolescents training curriculum have been developed by the Zambian Ministry of Health (2015) in collaboration with International Center for AIDS Care and Treatment Programs. This is aimed at empowering adolescents and caregivers with youth-friendly HIV care information. Also caregiver support was mentioned by Hodgson et al (2014) as a major facilitator of adherence among adolescents with a chronic disease, but this needs a lot of education on disease etiology among all those in this age group. This initiative could also mean that most interventions to promote adherence to cART among adolescent patients can easily be universally applied to enhance of knowledge on HIV and disease progression.

The findings in the current study are consistent with the demographic health survey report by CSO (2014) were it was as well reported that the comprehensive HIV knowledge among adolescents was also very low that is, 39% and 45% for females and males respectively. It could be argued that adolescents depend on healthcare providers for information about their health and cannot independently seek to acquire more knowledge about their health. Therefore health care providers must be proactively providing health related massages for the adolescents to acquire more knowledge about HIV and the disease progression.

Contrary to the current study, Mweemba et al (2015) in Zambia found 56.7 % of the adolescents had knowledge about their HIV status. Despite the reported knowledge it was found that adolescents had challenges with maintaining the desired 95% adherence threshold. The 95% adherence to cART has been strongly linked to viral suppression in most studies.

Similar to the current study UNICEF (2012) reported that the overall level of knowledge of HIV and AIDS remained very low among older adolescents aged 15-19. Interestingly to note that similar findings were reported by Kenu et al (2014) in Ghana that 47% of adolescents on cART had no knowledge about the HIV disease and its progression. These similarities could mean that adolescents have common interests and aspiration despite geographical variation. It could also mean that there is very little or no impact on the current trends of practice to enhance knowledge on HIV and disease progression. This is because low level of knowledge has kept on being reported hence the need for studies on impact assessment on the HIV care models implementation.

However, when adherence to cART was associated with knowledge of HIV and disease progression in the current study, the relationship was found to be independent. Having Knowledge about HIV and disease progression alone cannot prompt improved adherence to cART. This is evident in some more recent studies where despite high knowledge among HIV positive adolescents report (XU et al, 2017; Hornschuh et al, 2017; Kenu et al, 2014), it was found that they were non adherence to cART. It could be argued that acquisition of high level knowledge alone is not enough to promote adherence to cART among HIV positive adolescents. A holistic approach in devising interventions must be adapted as the most accurate measure to promoting adherence to cART among HIV positive adolescents. A combination of personal, interpersonal, community and societal interventions as prescribed by social ecological model levels could be the most effective approach to improving adherence to cART among adolescents.

The current study reported that understanding the reason why the respondents were taking cART was found to be strongly dependent with adherence to cART. Having understanding could mean having the ability to interpret and explain information about HIV and being able to estimate and anticipate undesired outcomes when there is poor adherence to cART. It is expected that those respondents who had understanding of the reason they were taking cART, also knew the consequences of non adherence. Therefore, they were compelled to be adherent to their cART to prevent disease progression and drug resistance.

Similar to the current study some studies elsewhere have also shown that having understanding of the benefits for taking cART could have a positive influence on cART adherence among HIV positive adolescents (Agwu and Fairlie, 2013). These finding suggest that promotion of adherence to cART, requires deeper level of knowledge about HIV and disease progression.

The current study established that 58% (56) of the respondents who were adherent to cART had low level knowledge. This could mean that the adolescents who acquire more knowledge feel that it is enough to prevent the disease progression. This is evident by higher pattern of adherence to cART by the respondents who had low knowledge 62% (47).There was no significant association between adherence to cART and the level of knowledge. The respondents who had low knowledge of HIV and disease progression had one time chance more to be adherent to cART than those who had high level of knowledge about HIV and disease progression. This could be due to the caregiver's strictness in ensuring that the adolescents are adherent to cART who may have low knowledge of HIV and disease progression. The adolescents who had low level of knowledge could also be depending on their buddies and healthcare providers for the instructions and care hence the higher rate of adherence to cART among those reported to have low level knowledge.

5.5. Social cultural factors influencing the respondents' adherence to cART.

5.5.1 Social support system

The majority (94.8% [164]) of the respondents reported to have adequate social support. These results could be that the current study site had better resources than many clinics in resource limited settings. The site also had a supportive environment that equipped adolescents with the appropriate skills to enable them to face the challenges of adolescence. This may in part explain the

documented adequate social support here. Similarly to the current study some scholars in earlier studies elsewhere also reported adequate social support. It was found that adequate social support improved patient's ability to be adherent to cART (WHO, 2011; Lee et al, 2015; Kahana et al, 2013). Without physical and psychological support, it would be very difficult for the adolescents to access healthcare services. The reported adequate social support could also mean that the adolescents with HIV are living in conducive and supportive environments. While the issues of poor social support exist commonly in resource-rich settings, they may be even more prevalent in resource-limited settings and affecting adherence to cART (Bygrave et al, 2012). On the contrary most studies reports indicates that social support is adequate in both resource-rich and resource-limited settings.

In the current study it was found that adherence to cART and social support were independent. Social support when associated with adherence to cART among HIV positive adolescents, there was no significant finding. This could be explained by the statistic that 92% (70) of the respondents in the current study who were non adherent to cART were reported to have adequate social support. It can be concluded that non adherence to cART by adolescents could be contributed by personal rather than interpersonal related aspects. This is deduced because being reminded to taking medications in the current study was found to be dependent of adherence to cART. A binary logistic regression was performed to ascertain dependence of being reminded to taking the cART and adherence to cART. The logistic regression model was statistically significant. The HIV positive adolescents need to be encouraged by others around them to continue with cART and all the clinical follow ups as scheduled for the success of treatment.

Unfortunately 41% (71) respondents had nobody to go to the hospital to collect their cART on their behalf. When adolescents miss their hospital appointments they could easily run out of drugs. Missing hospital appointments could interference with cART adherence hence drug sub-therapeutic serum concentration levels leading to viral mutations and viral resistance (WHO 2014). Essentially according to Ndiaye et al (2013) if a patient has ever missed a refill, he or she is more likely to miss some doses suggesting an increased risk of non adherence to cART even in the absence of ongoing refill problems.

Furthermore 80.3% (139) of the respondents reported that when they missed the hospital appointments, no follow up was made to establish the reason by the healthcare providers. In most

healthcare facilities in resource- limited settings, the health worker to patient ratios are overwhelming. The health workers may not easily remember which patients are missing their appointments due to large patient populations seen. The patient missed appointment tracking system would be the most ideal when dealing with large numbers of adolescents patients. Healthcare providers need to have an established patient appointment tracking system to easily identify adolescents who could be missing out on drug refills due to low or no family support. Those missing appointments 27.7% (48) reported finding it difficult sometimes to access healthcare. The fact that some adolescents find it difficult to access care to pick up cART medications, suggests existence of structural barriers. Therefore, practical assistance to adolescents makes them feel cared for when given help such as financial support for transportation and easy access to get some drug refills and clinical follow up appointments. Support from parents (both financial and social) was highly rated by respondents in a study by Taddeo et al (2013) as positive. The study suggested that reinforcement of family closeness, cohesiveness, and problem-solving skills with adolescents could help the adolescents to complete the tasks related to treatment successfully on the daily basis.

Peterson et al (2012) study findings agree that adolescents with extensive supportive social networks among healthcare providers, relatives and peers appeared to cope better with psychosocial challenges. The community is supposed to have social network systems in place aimed at identification and offering active support to HIV positive adolescents on cART. This is because adolescence is a critical stage of a persons' transition from childhood to adulthood. Fetzer et al, (2011) observed that not all adolescents living with HIV were ready to make transfer from children to adult care at the same time. Before any transfer of care, health care workers should take into account the HIV positive adolescents' cognitive and physical development and emotional maturity, their support at home and community.

5.5.2 Religious beliefs influencing respondents' adherence to cART

More than half (52.1% [90]) of the respondents in the current study believed that prayers and anointing oil could cure HIV/AIDS. Religious belief system has a very strong influence on an individual's life and behavior. Arrey et al (2016) cited that religion serves important roles in coping, survival and maintaining overall wellbeing within African cultures and communities, especially when diagnosed with a chronic disease like HIV/AIDS that can have a profound effect

on physical and mental health. However, spirituality/religion can be problematic to some patients and results in healthcare provision challenges.

Earlier Nozaki et al (2013) in Zambia showed that 17 % of participants believed that HIV could be cured by prayers and taking ART**.** Religious belief system that prayer and anointing oil could heal HIV/AIDS by some groupings seems to be gaining ground among HIV positive adolescents. The current study found that 9 % (15) of the respondents had at one point abandoned cART in preference of prayers. Researchers suggest that some religious beliefs and doubts about antiretroviral therapy among adolescents may be cultural specific, where faith-based healing is propagated by leaders of these faith communities. It is argued that health-related spiritual beliefs like calling on prayers or a higher power for protection to take control of health is common among patients with life-threatening diseases like cancer, mental illness, and HIV/AIDS (Kremer, (2016). Patients who accept such beliefs will not overtly reject cART when offered, but most often will not adhere to treatment and wait to report miraculous healing. It could be evident by report in the current study where 44.2% (68) respondents despite having positive religious beliefs were non adherent to cART. This could be that there is a mixed belief system between healing by prayer and cART adherence according to Kremer (2016). However, adherence to cART was found to independent of religious belief.

Elsewhere a study by Wanyama et al (2013) on ARV adherence in Uganda, found that 6 out of 558 (1.2%) adolescents discontinued their treatment because they believed that their pastors' prayers had cured them of HIV. Discontinuation of cART risk is gradually being reported and could actualize into health problem. Clergymen claiming healing powers need to start giving HIV clearance certificates following claims of curing HIV after offering prayers. This would protect the patients at risk of discontinuing medical treatment from seeking cure through prayers. These beliefs have already led to some adolescent patients to stopping cART after being promised to be cured of their HIV infection through prayers and anointing oil as evident in the current study report.

5.5.3 Stigmatization experienced by the respondents

In the current study generally it was reported that 57.2% (99) of the respondents had experienced high level of stigmatization. Despite the wide availability of campaign massages against stigma and discrimination, it's evident that there are socio-cultural misperceptions about the etiology and

spread of HIV/AIDS. This could be the reason for the high reported stigma in some parts of sub-Saharan Africa including in the current study.

Similar to the current study, Katz et al (2013) in Eastern Europe and Central Asia also reported high level of stigmatization with 61% HIV positive adolescents. The study also linked stigmatization to non adherence to cART. However this was contrary to the current study where adherence to cART and stigma was found to be independent. This could also suggest that in a long run stigmatized individual would eventually become non adherent to their cART. The current report showed that 41.6% (72) of the respondents felt that there was sometimes stigma and discriminations towards the people living with HIV in the community. This could be the reason for some respondents 8.7% (15) reported feeling uncomfortable even going to collect their medications from the clinic/hospital. Much more need to be done in the community to reduce the perceived stigmatization. Because of stigmatization HIV positive adolescents may not want to be known to have the disease. This makes most HIV infected adolescents feeling very angry with diagnosis and their parents who may have transmitted the infection to them. If not well handled this could affect the adherence pattern of their cART.

Consistent with the current report, Feldman et al (2012) in USA, also reported that 76% of adolescents experiencing HIV-related stigma. This impacted negatively on their routine taking of the cART. According to Fetzer et al (2011) observation, adolescents are often concerned about ‘‘feeling normal’’ and not feeling ‘‘different from their peers.’’ Apart from the inherent difficulty of repeatedly taking medications, adolescents sometimes skip cART doses because drugs are a reminder of the HIV infection that makes them different from others.

Among respondents that were non adherent to cART 63% (48) had high level of stigmatization. According to the WHO (2013) report, stigmatization leads to poor management of HIV/AIDS programs and violation of human rights for the HIV positive adolescents. When stigmatization is high, the affected adolescents could easily abandon their cART or even fail to follow up the scheduled clinical visits. This is evident where nearly one third 30.1% (52) of the respondents reported failing taking their cART because of friends, teachers or other people being around. During social outings away from home such as in camps and sporting activities, the HIV positive adolescents could be uncomfortable to take their antiretroviral drugs resulting in reduction of

therapeutic drug levels in their blood to suppress the viral load. This could lead to viral mutation and continued viral multiplication hence increasing the amount of HIV in the blood.

It must be stated that stigmatized individuals are more likely going to suffer social isolation and non adherence to their cART. Non adherence to cART prevents maximal and durable suppression of HIV replication.

In contrast to the current report, studies in Kenya and Uganda (Kaai et al, 2012; Tsai et al, 2013) have demonstrated decline in stigmatization among adult patients after a long period on ART. This observation is vital that reduction of stigmatization is a long term gradual process. This is supported by the findings of qualitative studies among people with HIV in Zimbabwe and South Africa, who generally attributed their improved self-image, functioning and wellbeing to the role of antiretroviral treatment (Campbell et al, 2011; Zuch and Lurie, 2012). It is expected that after a long time on cART the adolescents would be living quality lives free from opportunistic infections. When the attained quality of life is linked to adherence to cART, stigmatization would not affect the adherence.

5.6 Application of the theoretical framework

The investigation of factors influencing adherence to cART was done from the first level individual, second level interpersonal, third level organizational and fourth level community of the SEM. The findings fitted in model as discussed in the units below.

5.6.1 Individual Level influence

Low level of knowledge was identified to be very high among the study respondents. However, low level of knowledge was found to be independent of adherence to cART. However this was found that it could raise the risk of non adherence which subsequently could lead to persistently high viral loads among the HIV positive adolescents.

Furthermore, experiencing cART side effects was found to be dependant with non adherence to cART among the respondents. Literature has shown that drugs used in second-line cART are rarely tolerated by patients due to toxicity such as hypersensitivity reaction; kidney failure; progressive neuropathy and gastrointestinal complaints.

5.6.2 Interpersonal level influence

The study found that respondents had adequate social support just as expected that HIV positive adolescents need to get some support from other people as they take the lifelong cART. However stigmatization was reported to be very high among the respondents.

5.6.3 Community related influences

The model underpinned that in the community there is an emerging influence from some religious beliefs that HIV/AIDS could be cured by prayers and anointing oil. This is evident by some adolescents who had reported at one point abandoning taking cART in preference of prayers and anointing oil. If not addressed this belief system could have a negative influence and increase the risk of drug resistance and treatment failure when adolescents abandon cART for prayers.

5.7 Study limitations and strength

The study did not explore ways to follow up victims infected with HIV through rape to ensure justice. The study was limited to HIV positive adolescents enrolled at UTH, adult infectious diseases Centre -HIV care and treatment site. However a representative sample size was obtained to allow transferability and generalization of findings to adolescents in general population. Data were limited to respondents' responses to the questionnaire question items. Hence some experiences of the respondents that led to non adherence to cART were not provided from the responses.

The strength of the current study is that findings could be generalized because selection of samples was well designed and the sample was representative of the population. Data was very consistent and reliable hence this allows for generalizationability of the findings.

5.8 Implications of the study to Nursing

Adherence to cART among HIV positive adolescents is one of the integral interventions of curbing development of drug resistance and treatment failure.

5.8.1 Nursing Education

The study finding showed that 43.9% (76) of the respondents were non adherent to their prescribed cART and this could be the positive evidence based information and communication point aspect in nursing education. Notable deficiencies in knowledge of HIV and disease progression need to

be emphasized because once adolescents are well informed they could easily adopt positive living and improved adherence to cART.

There is need therefore to strengthen the teaching methodologies used when educating HIV positive adolescents about HIV and cART adherence. This may be achieved by providing the necessary mobile phone short massages audio-visual aids on television programmes and other multimedia forums.

Various teaching methodologies should also be utilized such as role plays and using experiences from clients who responded positively after following the adherence schedules correctly. There should also be continuing education to the nurses on support programmes to enhance adherence to cART.

5.8.2 Nursing practice

The current study has revealed that cART side effect, understanding reason for taking cART and being reminded to taking cART significantly influence adherence. The nurses should therefore be vigilant to detect early any side effects so that early interventions could be implemented to avoid chances of non adherence to cART.

It must be a practice to educate the adolescents on prompts to remind them to taking medications such as setting alarms, associating medication with some routine daily activities. This practice could promote adherence to cART among HIV positive adolescents.

5.8.3 Nursing Administration

Nurse administrators need to advocate for integrated HIV services to increase the level of cART adherence as it has serious and life threatening effects to adolescents and communities. Nurse administrators should ensure that the nurses handling these clients have been trained to offer advanced ART care, psycho socio counseling and organize refresher courses in HIV care from time to time. The Nursing administrators should also provide ongoing supervisory HIV care visits to the nurses to provide support and appreciate their work. More trained staff should also be allocated to handle the adolescents counseling session to avoid burn out among the nurses which can make the care to be ineffective.

5.8.4 Nursing Research

A lot of studies on adherence have been done globally and regionally. However, there is limited research conducted in Zambia on factors influencing adherence to cART among adolescents. Therefore, nurse researchers should utilize these findings as a foundation for further research in order to determine factors at individual, interpersonal, community and societal level to effectively and consequently contribute to the evidence based practice in nursing.

5.9 Conclusion according to the study objectives

The purpose of the current study was to determine factors influencing adherence to cART among HIV positive adolescents at Adult Infectious Diseases Center in Lusaka, Zambia. It was found that there was significantly high level of non adherence to cART among HIV positive adolescents. This implies prevalence of barriers against adherence to cART among HIV positive adolescents. The 95% or above adherence threshold is necessary for maintaining viral suppression; preservation of health and attainment of physical and psychological wellbeing.

The current study reported that the level of knowledge about HIV and the disease progression was low and social support was reported to be adequate. These study findings suggest that Health care providers and caregivers do play an important role in preventing non adherence to cART problems by addressing critical issues early.

The study also found that majority of the respondents had a positive religious belief system which did not affect adherence to cART. However few respondents were found to have the negative religious beliefs and these were reported to have abandoned their cART at one point in preference of healing through prayers and anointing oils. This could in a long run negatively affect adherence to cART.

The level of stigmatization was found to be very high among the respondents in the current study. However, when predictors variables (level of knowledge of HIV and disease progression, social support, religious beliefs and level of stigmatization) were associated with the outcome variable (adherence to cART), they were found to be independent. Therefore, the current study settled for the null hypothesis which stated that there was no relationship between adherence to cART (dependant variable) and Knowledge of cART treatment and disease process and social cultural factors (independent variables) among HIV positive adolescents.

Other factors such as understanding the correct reason for taking cART, experiencing cART side effects, being reminded to taking the drugs and just being satisfied with the care being provided were found to be dependent of adherence to cART.

The study findings suggest that once HIV positive adolescents understand need to take their cART, they would play a pivotal role to sustain adherence of 95% or more to the prescribed cART. This would lead to achievement of the benefits of sustained viral suppression for as long time as possible. Interventions to promote cART adherence must include provision of adequate knowledge about HIV and disease progression, ensuring sustenance of adequate social support, promoting positive religious belief systems and reducing the high levels of stigmatization.

5.10 Recommendations

To address the problem of non adherence to cART, support by Health care providers is essential until the adolescents' competency and responsibility are assured. Therefore directly observed antiretroviral therapy administration strategy by the buddies must be introduced among HIV positive adolescents since being reminded to taking cART was dependant to adherence.

More studies must be conducted in Sub-Saharan Africa to inform the development of culturally centered appropriate interventions and strategies to optimize cART adherence among adolescents.

The Individual targeted interventions such as enhancing HIV knowledge to improve understanding of the disease process using electronic animations could be an effective enhancer of adherence to cART among HIV positive adolescents.

More emphasis must be made by promotion of interpersonal focused intervention such as peer group support through sharing experiences hence mitigation of stigmatization and discrimination which was reported to be prevalent among HIV positive adolescents.

The Churches Association of Zambia (CHAZ) needs to pass a regulatory framework on who should speak about HIV cure among the Churches denominations and other religious groupings. This is to prevent some clergymen stopping HIV positive adolescents from taking their prescribed cART and replacing them with anointing oil and prayers. This practice has a great risk of viral mutation and virologic failure related to interruption of prescribed cART.

5.11 Plans for Dissemination of Findings

This study provides the body of evidence, to support HIV positive adolescents' clinical care, particularly in the aspect of adherence to cART and is a reliable source of evidence (Borbasi and Jackson, 2012).

Therefore, dissemination of preliminary findings was undertaken by the researcher to make known the new body of evidence to the relevant authorities (Hamer and Collinson, 2014; Polit and Beck, 2008).

The findings were disseminated at the Graduate presentation medium organised by the Directorate of Research and Graduate studies (DRGS)

A copy of the research report will be sent to management of the hospital under study, University of Zambia-School of Nursing Sciences, University of Zambia-Medical Library, Ministry of Health, Churches Health Association of Zambia and General Nursing Council of Zambia. This is aimed at helping inform these institutions implement evidenced based measures which could promote adherence to cART among HIV positive adolescents in Zambia.

The study report will also be published in the peer reviewed Journal to add to the existing body of knowledge.

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APPENDICES

Appendix 1: Participants information sheet form

FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG ADOLESCENTS AT ADULT INFECTIOUS DISEASES CENTRE LUSAKA, ZAMBIA

My name is **Harrison Namoomba** a student pursuing a Master of Science in Clinical Nursing at the University of Zambia, School of Nursing Sciences. I am kindly requesting for your participation in the research study mentioned above, because it is important to determine what affects adherence to cART among adolescents. I will initially explain the purpose of the study, the risks or benefits and what is expected of you. Your participation will entirely be voluntary and you will be requested to sign the consent form if you are agreeable. However, if you decline to participate you won't have to sign the consent form and this will attract no penalty.

Purpose of the study

The study determined factors influencing adherence to antiretroviral therapy among adolescents at adult infectious diseases centre Lusaka, Zambia.

This is to help The University Teaching Hospitals, Adult Hospital management and stakeholders to devise measures to promoting adherence to cART.

Procedure

The study involved signing of the consent form and completing the guided questionnaire. Once completed, the researcher retained the questionnaire for processing.

Risks and discomforts

There were some temporal emotional or psychological trauma from answering some questions concerning the illness and long life treatment. Part of participant's time was spent answering some questions and this may have resulted in some bit of discomfort. No further discomfort was experienced before during and after the process of collecting data from the participants.

Benefits

There were no direct benefit by participating in this study, but the information which was obtained would help the stakeholders and policy makers to minimize cART non adherence among adolescents. The information obtained shall be used to improve the care for the HIV positive adolescents for them to be remained on cART for as long as possible without developing drug resistance and treatment failure.

Cost, reimbursement and compensation

Participation in this study was voluntary. Participants did not receive money for their participation. However, those that felt like withdrawing at any time were free to do so and this did not affect their care at the facility in any way.

Confidentiality/anonymity

The data which was collected did not contain any personal information about participants and all information collected in this study was kept strictly confidential. No one linked the participant to information provided (e.g., address, email).

For further information

We would be glad to answer your questions about this study at any time. You may contact us by writing, phone or email to;

1. **The Chairperson, University of Zambia, Research Ethics Committee, P. O. Box 50110, Lusaka. email unzabrec@unza.zm**
2. **Principal Investigator, University of Zambia, School of Nursing Sciences, P. O. Box 50110, Lusaka. email harrisonamoomba@gmail.com, Mobile +260955332021**

PEPALA LA CIDZIWITSO

ZOMWE ZIKUZA KUGONJELA KUMWA MANKWALA YA KADOYO KA HIV/AIDS PAKATI PA ANYAMATA NDI ATSIKANA PACHIPATALA CA UTH LUSAKA ZAMBIA.

Dzina langa ndine **Namoomba Harrison** ocita maphunzilo oyanganira mbali wosamalira odwala muchipatala pa sukulu ya UNIVERSITY OF ZAMBIA. Ndili kupempha kugwapo kwanu mu phunziloli wofunsila cifukwa ncofunikira kudziwacomwe cilengetsa acicepele kulekeza kumwa mankwala pakati **.** Ndidzakudziwitsani zocokamo mu muphunziroli zoopsa ndi ubwino wace . kugwapo kwanu ndikuzi peleka , ngati simufuna ku funsidwa musa saine cipepala ici kopanda kuopa .

COLINGA CA PHUNZIRO.

Phunziloli tiyesa kupeza zifukwa zomwe zidzeta kuleka kumwa mankwala HIV/AIDS pakati pa acicepele pacipatala ca UTH .Ici cidza thandizila cipatala ndi wothandizila kupeza njila zo thandiza ana kusaleka kumwa mankwala .

NJIRA.

Kudzakala kusayina cipepala ca kuvomeleza kufunsidwa ndi kuyankha mafunso pakutsiriza kuyankha , wofunsa azabweletsa cipepala kuti mayankho akonzedwe .

CIWOPSEZO KOMANSO KUSOKONEZA.

Ziliko zosa nvetsa bwino mukuyankha mafunso awa kulingana ndi zomwe munvela pakukala ndimatenda aya ndi umuyo wa kumwa mankhwala Mukatsiliza kulibenso zina zoopsa muzazimbva.

PHINDU .

Sikudzakala kuliplidwa mukufunsidwa mafunso a phunziloli , koma mayankho yanu yaza thandiza wothandiza ndi boma kuyesa kupeza njila zocepesa kulekeza kumwa mankwala ndi kupeleka nthandizo mukusamalira odwala matenda monga anu ,ndikuyesa kuthandiza acicepele odwala HIV/ AIDS kusaleka kumwa mankwala , ndikuna kusewenza kwa mankwala cifukwa ca kisiya kumwa mankwala ..

MUTENGO ,WOBWEZELA NDI MALIPIRO.

Kutengako mbali kwanu ndi kuzipeleka simudzalandila malipiro .Ngati mufuna kusiya mungasiye kopanda kusokoneza kulandira mankhwala pacipatala.

CINSINSI\KUSADZIWIKA

Zotuluka muphunziloli dzina ndi za umwini zambili sizidzaculidwa

KUDZIWA ZAMBILI .

Ngati mufuna kudziwa zina pa phunziloli tumilani lamwa kunambala iyi kapena lembelani

1. **The Chairperson, University of Zambia, Research Ethics Committee, P. O. Box 50110, Lusaka. email unzabrec@unza.zm**
2. **Principal Investigator, University of Zambia, School of Nursing Sciences, P. O. Box 50110, Lusaka. email harrisonamoomba@gmail.com, Mobile +260955332021**

Appendix II: Consent form

Participants Form

The purpose of this study has been explained to me and I understand the purpose, the benefits, risks and discomforts and confidentiality of the study. I further understand that taking part in the study is purely voluntary, if I accept to take part in this, I can withdraw at any time without having to give an explanation.

I, _____ _____ (Names)

Agree to take part in this study.

Signed _____Date: _____ (Participant)

Participants' signature or thumb print

Signed: _____Date: _____ (Witness)

Signed: _____Date:

_____(Researcher)

We will be glad to answer your questions about this study at any time. You may contact us by writing, phone or email to;

1) **The Chairperson, University of Zambia, Research Ethics Committee, P. O. Box 50110, Lusaka. email unzabrec@unza.zm**
2) **Principal Investigator, University of Zambia, School of Nursing Sciences, P. O. Box 50110, Lusaka. email harrisonamoomba@gmail.com, Mobile +260955332021**

Cipepala ca kudziwitsidwa ca otengako mbali ca akulu

Lingo ya mphunzilo iyi andimasulila , phindu lace,zoopsa ndizosa kondweletsa zotuluka mu phunzilo iyi .Ndivomekeza kuti kutengako mbali ku phunzili ndi kuzipeleka mosakakamizidwa ayi ngati ndabvomera. koma ngati ndifuna kusiya nthawi ili yonse, ndingacoke kopanda kupeleka zifukwa zilizose.

INE…… (DZINA) ndibvomekeza kutengako mbali muku fufuza kwa phunzilo iyi……. (kusaina)

WOFUFUZA……../…….

Appendix III: Assent Form for Children

Research Title: FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG ADOLESCENTS AT ADULT INFECTIOUS DISEASES CENTRE LUSAKA, ZAMBIA

Participants Form

I have read the participation information sheet and have had the opportunity to ask the researcher any further questions I may have had. I understand that my participation in this research is voluntary and I may withdraw at any time from the study without affecting my treatment at this hospital in any way.

I understand that the risks and discomforts to me are minimal in this study and have read the information sheet and asked any questions I may have about the risks.

My name will not be used to identify my comments or work in the study. If I have any concerns or complaints regarding the way the research is or has been conducted I can contact the University of Zambia Biomedical Research and Ethics Committee at unzabrec@unza.zm**.**

I understand that information from me will be used for a thesis and possibly other published studies and I consent for it to be used in this manner.

I give permission for my child _____ to participate in this research. (Child's name)

Parent/ Guardian Signature _____ Date_____

Name (please print) _____

Child's signature _____

Researcher's signature: _____

Cipepala ca kudziwitsidwa ca otengako mbali ca ana

MUTU WA PHUNZILO: ZOMWE ZIKUZA KUGONJELA KUMWA MANKWALA YA KADOYO KA HIV/AIDS PAKATI PA ANYAMATA NDI ATSIKANA PACHIPATALA UTH LUSAKA ZAMBIA.

Ndawelenga chipepala chakutengako mbali ku phunziro ndimafunso ya iyi phunzilo. Ndapatsidwa mpata wa kufunsa mafunso yomwe ndinali nayo pa iyi phunzilo, ndibvomekeza kuti kutengako mbali kumafunso ya phunziloyi sikukakamizidwa ayi ,ngati ndabvomera , koma ndika nganiza kusiya ndinga siye kopanda kusokoneza khalidwe langa pa pa cipatala pano.

Ndibvomekeza kuti zokondweretsa ndizosakondweretsa zocoka kuma funso a mu phunzilo iyi ndawelenga ndikufunsa mafunso yomwe ndinali nayo kucokera muzolembedwa muchipepala ichi ca mafunso pa zoopsa zingathe kuchomo mu phunziloyi.

Ndzina langa siidza culidwa mu zotuluka muphuniziloli ,ngati ndili ndimanadandaulo pa zo tulukamo, ndingathe kulembela bumgwe la BIOMEDICAL RESEARCH CENTRE KU UNIVERSITY OF ZAMBIA.

Ndibvomekeza kuti mayankho yanga ndi zokamba zanga zi sewenzesedwe ku zolemba zo choka ku phunziloiyi

Ine …….ndibvomekeza kuti mwana wanga atengeko mbali kumfunsidwa kwa mu phunzilo iyi.

DZINA YA
MWANA…….TSIKU……..

KUSAYINA/CHIZINDIKILO……..…….

WOFUFUZA……../…….

Appendix IV: Questionnaire

UNIVERSITY OF ZAMBIA

SCHOOL OF NURSING SCIENCES

TITLE FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG ADOLESCENTS AT ADULT INFECTIOUS DISEASES CENTRE LUSAKA, ZAMBIA

DATE: …… SERIAL NO……..…

Section A. the demographic data,

1. Are you:
   a) Male
   b) Female
   c) Transgender
2. As of today, how old are you?
   a) 16-17 years of age
   b) 18-19 years of age
3. What is the highest level of education that you have completed?
   a) Primary
   b) Secondary (high school)
   c) Tertiary (college, university, or vocational training)
   d) Other (please specify)
4. Where do you live?
   a) Homeless
   b) Orphanage/care home
   c) Live with friends
   d) Live with family
   e) Live alone
   f) Other (please specify)

5. Who is your care giver?
    a) Biological Parents
    b) Grandparents
    c) Uncle/Aunty
    d) Others specify----------
6. Which status is applicable to you?
    a) Both parents alive
    b) Father alive
    c) Mother alive
    d) Both parents died

Section B: Adherence assessment

7. People sometimes forget to take their medications, have you ever forgotten to take your medicine?
    a) Yes
    b) No
8. Do you find it difficult at times to taking your medicines?
    a) Yes
    b) No
9. When you feel better, do you sometimes stop taking your medicine?
    a) Yes
    b) No
10. Sometimes if you feel worse when you take the medicine, do you stop taking it?
    a) Yes
    b) No

If the participant answers negatively to just one out of 4 questions, it is defined as 'non-adherence'.

Section C: Level of Knowledge on cART treatment and disease process

11. Are you living with HIV?
    a) Yes
    b) No
    c) I do not know
    d) I do not wish to disclose
12. If Yes to Question 11, how did you get HIV?
    a) From my mother
    b) Through sexual activities
    c) Through drug use (contaminated needle or syringe)
    d) From a blood transfusion, exposure to infected blood, or a medical procedure (injections, etc.)
    e) I do not know
    f) Other (please specify)
13. You are currently taking medication for HIV; do you feel you adequately understand why you are taking it?
    a) Not at all
    b) Sometimes
    c) Very much
    d) I do not take medication for HIV
14. Do you know which cART drugs you were started with?
    a) None Nucleotide Reverse Transcriptase Inhibitor (NNRTI)-based
    b) Protease Inhibitor-based
    c) Treatment interruption on mono/dual therapy
15. Do you have side effects from your treatment?
    a) No
    b) Yes, specify……..…
16. How many years have you been taking the cART?
    a) Less than 5 years
    b) Between 5 to 10 years
    c) Above 10 years

17. Is somebody giving you your treatment?
    a) No, I take it by myself
    b) Yes
    c) If Yes Who? Specify.....
18. Is somebody reminding you to take your treatment?
    a) Never
    b) Sometimes
    c) Always
19. Do you find it easy or difficult to remember to take your treatment?
    a) Very Easy
    b) Easy
    c) Difficult
    d) Very difficult
20. Do you use any tricks to prepare or remember to take your treatment on time? (tick all that apply)
    a) None
    b) Clock/watch alarm
    c) Cell phone alarm
    d) National anthem
    e) TV / radio program
    f) Use pill box
    g) Other: ……
21. During the last week (7 days), did you ever forget to take your treatment?
    a) Never
    b) I forgot one dose
    c) I forgot several doses
    d) Don't know
22. If you ever forget to take your medication, what was the main reason?
    a) I was sick
    b) I was playing
    c) I was too busy

d) I was fed up

e) I was not at home

f) It was a festival/holidays

g) I was not given them

h) There wasn't enough privacy

i) Other reasons, specify……

23. Do you know your recent CD4 cell count**;**

a) Absolute count

b) Percentage (%)

24. Do you know your recent viral load measures while on cART

a) Yes

b) No

c) Not sure

25. Have you suffered from any opportunistic infection while on this treatment?

a) Yes

b) No

26. If Yes to question 25 please specify----------

27. Why do people develop opportunistic infections while on cART?

a) Because of missing their drugs

b) It has nothing to do with missing drugs

c) When they take the drugs for too long

d) When they stop taking the drugs

Section D: The social support of the HIV positive adolescents

28. How easy is it for you to access your health care?

a) Very easy

b) Sometimes easy, sometimes difficult

c) Very difficult

29. How long do you have to travel to get to your health-care provider(s)?

a) Under 15 minutes

b) 15 – 30 minutes

c) 30 minutes – 1 hour

d) More than 1 hour

30. Which of the following people give you emotional and practical support like transport to the clinic? (check all that apply)
    a) Family
    b) Friends
    c) Religious/faith community
    d) Health-care provider(s)
    e) Peer support group with other young people living with HIV
    f) Other (please specify)----------
31. How do you pay for your health care? (check all that apply)
    a) I attend a free clinic
    b) I pay
    c) My parents/family pay
    d) My insurance company pays
    e) The government pays
    f) I do not know
    g) Other (please specify)----------
32. What type of health-care provider do you see you?
    a) Medical doctor
    b) Nurse
    c) Community health worker
    d) Lay counselor/ health advisor
    e) Traditional healer
    f) Pastor
    g) If other, please specify
33. How often do you see them?
    a) At least once a month
    b) Every 1-3 months
    c) Over 3 months

34. When you are unable to come to the hospital, who comes on your behalf to collect the drugs
    a) Social worker
    b) Family member
    c) Teacher
    d) Friends
    e) Nobody
35. Do you feel that attending appointments with health-care providers interferes with your life?
    a) Not at all
    b) Sometimes
    c) Very much
36. If you miss an appointment with a health-care provider, does someone contact you to see why?
    a) No
    b) Yes, by phone call or SMS
    c) Yes, by letter
    d) Yes, by contacting my parents
    e) Yes, by sending someone to my home
    f) Other (please specify)

Section E: Religious beliefs that could lead to non-adherence to cART

37. Which religious grouping do you belong?
    a) Christianity
    b) Hinduism
    c) Muslim
    d) Others specify----------
38. Do you believe that prayer and oil anointing can heal sickness?
    a) Yes
    b) No
    c) Not sure

39. If yes to question 38, have you then at one point abandon treatment from hospital in preference to prayers
    a) Yes
    b) No
40. Have you at any point taken traditional medicines to try and cure your illness?
    a) Yes
    b) No

Section F: Stigmatization among HIV positive adolescents.

41. Do you fail to take your medications sometimes because of friends, teachers or other people being around?
    a) Yes
    b) No
    c) Sometimes
42. Do you feel uncomfortable going to collect your medications from the clinic
    a) Yes
    b) No
    c) Sometimes
43. Do you feel that there is stigma and discrimination towards people living with HIV in your community?
    a) Not at all
    b) Sometimes
    c) Very much
44. Do you feel more should be done in your community to address stigma and discrimination towards people living with HIV?
    a) Not at all
    b) Sometimes
    c) Very much

Section F: Other factors that can affect adherence to cART among HIV positive adolescents

45. What makes you not to taking your medications sometimes?
    a) ----------
    b) ----------

c) ----------

46. How satisfied are you with your care for HIV?
    a) Not at all
    b) Somewhat
    c) Very much
    d) I do not receive care for HIV
47. What would you recommend as a best way to overcome non adherence to cART
    a. ----------
    b. ----------
    c. ----------

Appendix V: Variables marking key for the study

SECTION B: Adherence to cART Assessment			
Question number	**Question**	**Possible answers**	**Maximum score**
7.	People sometimes forget to take their medications, have you ever forget to take your medicine?	Yes No	1 0
8	Do you find it difficult at times to taking your medicines?	Yes No	1 0
9.	When you feel better, do you sometimes stop taking your medicine?	Yes No	1 0
10.	Sometimes if you feel worse when you take the medicine, do you stop taking it?	Yes No	1 0
Section C: Level of Knowledge on cART treatment and disease process			
11	Are you living with HIV	Yes No I do not know I do not wish to disclose	1 0 0 0
12	If Yes to Question 11, how did you get HIV?	From my mother Through sexual activities Contaminated needle Blood transfusion, I do not know Other (please specify)	1 1 1 1 0 1
13.	You are currently taking medication for HIV; do you feel you adequately understand why you are taking it?	Not at all Sometimes Very much I do not take medication for HIV	0 1 2 0
14.	Do you know which cART drugs you were started with?	None Nucleotide Reverse Transcriptase Inhibitor (NNRTI)-based Protease Inhibitor-based Treatment interruption on mono/dual therapy	1 1 1
15.	Do you have side effects from your treatment?	No Yes,	 1
16.	How many years have you been taking the cART?	Less than 5 years Between 5 to 10 years Above 10 years	1 1 1
17.	Is somebody giving you your treatment?	No, I take it by myself Yes If Yes Who? Specify.....	1 1
18.	Is somebody reminding you to take your treatment?	Never Sometimes Always	2 1 1

19.	Do you find it easy or difficult to remember to take your treatment?	Very Easy Easy Difficult Very difficult	2 1 0 0
20.	Do you use any tricks to prepare or remember to take your treatment on time? (tick all that apply)	None Clock/watch alarm Cell phone alarm National anthem TV / radio program Use pill box	0 1 1 1 1 1
21.	During the last week (7 days), did you ever forget to take your treatment?	Never I forgot one dose I forgot several doses Don't know	2 0 0 0
22.	If you ever forget to take your medication, what was the main reason?	I was sick I was playing I was too busy I was fed up I was not at home It was a festival/holidays I was not given them There wasn't enough privacy	0 0 0 0 0 0 0 0
23.	Do you know your recent CD4 cell count**;**	If Yes Absolute count Percentage (%)	1 1
24.	Do you know your recent viral load measures while on cART	Yes No Not sure	2 0 0
25.	Have you suffered from any opportunistic infection while on this treatment?	Yes No	1 0
26.	If Yes to question 25 please specify---------	Mentioning OI	1
27.	Why do people develop opportunistic infections while on cART?	Because of missing their drugs It has nothing to do with missing drugs When they take the drugs for too long When they stop taking the drugs	1 0 0 1
Section D: The social support of the HIV positive adolescents			
28.	How easy is it for you to access your health care?	Very easy Sometimes easy, sometimes difficult Very difficult	2 1 0
29.	How long do you have to travel to get to your health-care provider(s)?	Under 15 minutes 15 – 30 minutes 30 minutes – 1 hour More than 1 hour	1 1 1 0

30.	Which of the following people give you emotional and practical support like transport to the clinic? (check all that apply)	Family Friends Religious/faith community Health-care provider(s) Peer support group with other young people living with HIV Other (please specify)----------	1 to each
31.	How do you pay for your health care? (check all that apply)	I attend a free clinic I pay My parents/family pay My insurance company pays The government pays I do not know Other (please specify)----------	1 0 1 1 0
32.	What type of health-care provider do you see you?	Medical doctor Nurse Community health worker Lay counselor/ health advisor Traditional healer Pastor	2 2 1 1 0 0
33.	How often do you see them?	At least once a month Every 1-3 months Over 3 months	1 1 1
34.	When you are unable to come to the hospital, who comes on your behalf to collect the drugs	Social worker Family member Teacher Friends Nobody	1 1 1 1 0
35.	Do you feel that attending appointments with health-care providers interferes with your life?	Not at all Sometimes Very much	2 1 0
36.	If you miss an appointment with a health-care provider, does someone contact you to see why?	No Yes, by phone call or SMS Yes, by letter Yes, by contacting my parents Yes, by sending someone to my home	0 1 1 1 1
Section E: Religious beliefs that could lead to non-adherence to cART			
37.	Which religious grouping do you belong?	Christianity Hinduism Muslim Others specify----------	1 1 1 1

38.	Do you believe that prayer and oil anointing can heal sickness?	Yes No Not sure	1 1 0
39.	If yes to question 38, have you then at one point abandon treatment from hospital in preference to prayers	Yes No	0 1
40	Have you at any point taken traditional medicines to try and cure your illness?	Yes No	0 1
Section F: Stigmatization among HIV positive adolescents.			
41	Do you fail to take your medications sometimes because of friends, teachers or other people being around?	Yes No Sometimes	0 1 0
42	Do you feel uncomfortable going to collect your medications from the clinic	Yes No Sometimes	0 2 0
43	Do you feel that there is stigma and discrimination towards people living with HIV in your community?	Not at all Sometimes Very much	1 0 0
44	Do you feel more should be done in your community to address stigma and discrimination towards people living with HIV?	Not at all Sometimes Very much	1 0 0

KEY

1. **Section B:** Adherence to cART Assessment
   - Adherence to cART 4
   - Non adherent to cART 1-3
2. **Section C:** Level of Knowledge on cART treatment and disease process
   - High level 12 scores and above
   - Low level 1-11
3. **Section D:** The social support of the HIV positive adolescents
   - Adequate support 5 scores and above
   - Inadequate support 1-4
4. **Section E:** Religious beliefs that could lead to non-adherence to cART
   - Positive beliefs 3-4
   - Negative beliefs 1-2
5. **Section F:** Stigmatization among HIV positive adolescents
   - High 1-2
   - Low 3-4