FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG HIV POSITIVE ADOLESCENTS AT SELECTED DISTRICT HOSPITALS'CATCHMENT AREA IN RWANDA

By

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Master of Science in Nursing, Pediatric Track

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In the College of Medicine and Health Sciences

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July, 2019

DECLARATION

I do hereby affirm that this research project submitted in partial fulfillment for the award of masters of sciences in Nursing at University of Rwanda, College of Medicine and Health Sciences is our resourceful effort that was not submitted previously to somewhere else.

In addition, I also declare that a completed list of reference is mentioned to indicate the origin of the information cited.

HABUMUGISHA Emmanuel **Date: 29/ 07/ 2019**

Signature

DEDICATION

Almighty God for all guidance towards to us.

My wife NYISHIMIRENTE Sylvie,

My daughter,

My supervisors,

My parents

My friends

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Extra-ordinary gratitude to Heavenly Father, for his kindness to give us power, life, perseverance courage, and success of this research proposal.

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ABSTRACT

Introduction: HIV/AIDS has no cure; however antiretroviral therapy is used to reduce the viral load and improve the eminence of life of people living with HIV. Adolescence is experienced occasionally to sexual high-risk behavior and a lack of engagement with healthcare services that can influence adherence to antiretroviral therapy (ART).

Objectives to the study: This study intended to assess the level of adherence and factors influencing adherence to antiretroviral therapy among HIV positive adolescents at Gitwe and Ruhango district hospitals' catchment area in Rwanda

Methodology: Non-experimental, descriptive cross sectional design using quantitative approach was used. Stratified random sampling was used also to select 166 adolescents among 283 HIV positive adolescents followed in 17 health facilities of Gitwe and Ruhango district hospitals. A close ended questionnaire was used to collect the data. Data entrance and coding were completed via SPSS, version 21. Data analysis was done using both descriptive and inferential statistics with CI set at 95% and p-value >0.05. Ethical consideration was maintained in this study where this study was conducted after obtaining approval from the IRB at UR-CMHS and permission to collect data was also obtained from Gitwe and Ruhango district hospitals.

Results: The study found unsatisfactory adherence among the participants where over half of the adolescents (81.9%) were having poor adherence to ART, 16.3% were having moderate while only 1.8% were having high adherence.

This study showed some factors which were influencing positively adherence to ART like the extent to which the clinical staff helped the adolescents to take medication with a *p=0.000* and the extent to which the parents/guardians helped the adolescents to take medication had also a *p=0.000,* someone remembered the adolescents to take medication with a *p=0.001.*

This study also revealed some factors that were influencing adherence negatively like missing of any prescribed drugs with a *p=0.013,* forgetfulness with a *p=0.009,* dosage too complex with a *p=0.044,* isolated by family members with a *p=0.012.*

Conclusion: Poor adherence level was found. The planners and implementers of ART need to set up programs for poor adherence predictor's reduction.

Key words: Factors, Antiretroviral therapy, adolescents and adherence.

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS: Acquired Immune Deficiency Syndrome

APAG: Association des parents Adventististes de Gitwe

ART: Antiretroviral therapy

AYA: Adolescent and young adult

AM: Ante Meridiem (Before Noon)

CD4: Cluster Differentiation 4

CI: Confidence Interval

CMHS: College of Medicine and Health Sciences

CT: Central Tendency

DH: District Hospital

df: degree of freedom

GBV: Gender based violence

H/C: Health Center

HIV: Human immunodeficiency virus

LMICS: Low and Middle Income Countries

OR: ODDS Ratio

PMTCT: Prevention of mother to child transmission

PM: Post Meridiem (After Noon)

P value: Probability Value

RBC: Rwanda Biomedical Center

RNA: Ribonucleic Acid

RWF: Rwandan Franc

RDHS: Rwanda Demographic Health Survey

SPSS: Statistical Package of Social Sciences

TSAM: Training Support and Access Model

UNAIDS: United Nations HIV/AIDS

UR: University of Rwanda

VCT: Voluntary Counseling and testing

%: Percentage

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CHAPTER ONE: INTRODUCTION

1.1. INTRODUCTION

Around 13.6 million people are on the treatment of antiretroviral drugs globally that promote the survival of people suffering from HIV and progressively decrease the incidence of infection (Barnabas and Celum, 2015).

In Rwanda, since June 2014 the total number of 133,574 adult people and adolescents were on antiretroviral therapy and also many of them were receiving the first line regiment (MoH, 2016). In the beginning of July, 2013 to June, 2014, the total number of 2,212 children were enrolled in pre- ART program and this brought all children receiving antiretroviral drugs to 7, 853 (RBC, 2014). Adequate adherence to ART (> 95%) was found as the key principle to improve the welfare of people living with HIV including adolescents and dropping the possibility of getting opportunistic infections and non adherence becomes when the adherence level is less than 95% (MoH, 2016) and also Dachew, Tesfahunegn and Birhanu, (2014) supported that taking more than 95% of prescribed medication is recommended for optimal virologic suppression and to reduce the rate of treatment failure where virologic failure is linked with less than 95% of adherence rate.

At Gitwe and Ruhango district hospitals' catchment area, 283 adolescents are enrolled in the services of ART and over half of the adolescents (81.9%) were having poor adherence to ART, 16.3% were having moderate while only 1.8% were having high adherence according to the findings observed in this study. So the researcher was inspired to carry out this survey at that site in order to rule out the factors influencing adherence to ART amongst those HIV positive adolescents.

This chapter is composed of background of the study, purpose of the study, problem statement, significance of the study, objectives of the study, research questions, and definitions of key terms.

1.2. BACKGROUND

From its discovery, Human Immunodeficiency Virus (HIV) is still a main public health threat problem in the word (Granich, 2017). Globally, 1.0 million of people had died as a result of HIV related causes in 2016, there were about 36.7 million persons living with HIV at the end of 2016 with 1.8 million persons became newly infected in 2016 worldwide(WHO, 2017). Around 54% of adults and 43% of children surviving with HIV currently are getting constant antiretroviral therapy. Global coverage of antiretroviral therapy for pregnant and breastfeeding women suffering from HIV is elevated at 76% (WHO, 2017).

According to World Health Organization, Africa is mainly the affected area, with almost 25.6 million persons suffering from HIV in 2016 (WHO, 2017). The African countries account for about two thirds of the global entirety of new HIV infection (Granich, 2017). Adolescents (10-19 years) are affected by this life-threatening infection and HIV/AIDS is the number one causative agent of death among this age-group (WHO, 2017).

Globally, 2.1 million adolescents aged 10-19 years were suffering from HIV since 2012 and the majority of them (about 1.7 million) were living in Sub Saharan Africa accounting for 85% of all adolescents suffering from HIV (Murray, et al, 2017). In addition, more than a half (1.3 million) of adolescents living with HIV was in Southern and Eastern Africa. Outside Africa, 6% of the total adolescents suffering from HIV have been living within South Asia, 3.8% in Latin America and Caribbean, 5.2% in East Asia and Pacific, 1% in Central Asia and Eastern Europe and also 0.8% in Middle North and East Africa (Idele *et al.*, 2014).
Current report from Word Health Organization, 1.8 million adolescents among the ages of 10 and 19 years were living with HIV in 2016 worldwide and 80% of them also live in Sub Saharan Africa where Rwanda is situated (WHO, 2017).

Rwanda's HIV/AIDs prevalence rate among the general population was not changing from 2005 and remained on 3 % in the people aged with 15-49 where 4% were females and 2% were males. The high rate of HIV infection is more likely found in urban than in rural region (6 % and 2 %, specifically) because it is also high in Kigali city (6%) as there is no significant difference rate of HIV within the remaining provinces (2% to 3%). Only a very small number of children age between 0-14 are living with HIV (below 1 %) (RDHS, 2014).

HIV/AIDS has no cure; however antiretroviral therapy is used to reduce the viral load and advance the quality of life of people suffering from HIV. WHO recommends that antiretroviral drugs must be initiated in adolescents suffering from HIV despite of clinical stage and CD4 count with strong recommendation to those with clinical stage 3 and 4 and those with CD4 cell count of below or equivalent to 350 cells/mm^3 (Oguntibeju, 2012). Despite this recommendation; different authors have confirmed that adolescents have different hindrance to access the HIV treatment. According to Hudelson and Cluver, (2015),in low and middle income countries, adherence to antiretroviral has to be considered as key element among HIV positive adolescents people on antiretroviral treatment even thought these persons have a particular challenges to drug adherence.

In a study performed in 3 clinics found in Palapye District, at Central region of Botswana aimed at describing most important factors that influence adolescent adherence to antiretroviral treatment , the average adherence level for the whole sample was 76.96%, and Poor processing of disclosure, waiting time and due distance, accessibility of health facilities, the nature of feelings and social support toward receiving of antiretroviral, stigma have been found as general factors predisposing to non-adherence in adolescent people (Kambale, 2013).

Further study in Kenya revealed that poverty, stigma, cultural and religious beliefs and lack of social support hampered persons suffering from HIV/AIDS's adherence to antiretroviral therapy in Siaya County and indicated also that the majority of PLWHA did not afford the costs of medication for opportunistic infections, transport to health facilities and nutritious diet, all of which are important for successful adherence to ART (Dan, 2016).

Furthermore a study done in Zambia since 2016 showed that adult people around 12.4 % was surviving with Human Immune deficiency Virus and 11,000 adolescents had been diagnosed newly HIV positive where only 67% of adult patients and 52% of adolescents were receiving antiretroviral drugs and this study demonstrated that main adolescent health problems in the whole country were related to lack of information regarding HIV, premature beginning of sexual intercourse, sexual transmitted infections and teenage pregnancies (Okawa et al, 2018).

In ART medication, the adherence level must be at least 95% of doses for accomplishing long term benefits of antiretroviral therapy and this is the duty of health care personnel to rule out

some factors that may affect adherence and reinforce counseling for maximizing the adherence level at least above 95% and those factors that can hinder adherence are drug related issues like adverse effect to ART, patient related issues like age and poor expectation from therapy, child refusal, child- caregiver relationship, caregiver related issues, forgetfulness, lack of food (poverty) and system related issues like inconsistence availability of drugs (MoH, 2016).
In Rwanda also, important progress has been done in improving the accessibility to ART among youth and this availability to ART increased progressively but adherence remains essential for minimizing poor clinical outcomes on transmission of HIV, unfortunately according to the survey done by Fawzi,et al (2016) reviewed that around 37% of youth refused to take ART and their non adherence was associated with mental health issues, depression (26%), 12% attempted to kill oneself.

According to Dachew, Tesfahunegn and Birhanu, (2014) the antiretroviral therapy efficacy for suppressing replication of virus and delay in the progress of acquired immunodeficiency syndrome has a relative for the optimum drug adherence. On the other hand, clarifying the magnitude and the factors related with non–adherence to antiretroviral treatment was important for designation of interventions responsible to improve drug adherence and outcome of health to antiretroviral treatment (Mukui *et al.*, 2016).

Rwanda provides universal access to lifesaving antiretroviral treatment for those in need and has prioritized the early initiation of antiretroviral drugs, whereby ART is provided free of charge to those who are HIV positive. The country has also promoted designation of responsibility (Task Shifting) from physicians to the professional nursing staff of ART services (RBC, 2013) despite the availability and accessibility of ART for everyone in Rwanda. With this availability and accessibility of ART in Rwanda; it is expected that the adherence be 100%. However there is a non-adherence level particularly among adolescents. For example the report from our selected study areas demonstrated that 39.5% of adolescents on ART have non-adherence. This has aroused the researcher interest to find out factors influencing this non-adherence. Basing to that non adherence rate, the researcher has assessed the factors influencing non adherence to antiretroviral at a selected district hospitals' catchment area in Rwanda.

1.3 PROBLEM STATEMENT

A study conducted in Rwanda by Mutwa R, et al. (2013) showed that only 45% of children including adolescents had taken all of their prescribed combined ART medication in previous months and this study revealed that there was a significant higher adherence associated with better understanding of combined ART and some of the barriers to the adherence highlighted in this study were; physical and emotional changes, being orphaned, stigma and school conditions whereas poor adherence is the major cause to the treatment failure, HIV resistance, disease progression and HIV transmission while 95% of combined ART adherence is associated with reduced morbidity and mortality therefore adherence has to be one of the main concern when administering ART.

ART adherence is crucial for successful treatment mostly clinical significant viral load reduction even if there are some factors impacting adherence like human behaviors and beliefs, inadequate knowledge and negative attitudes towards ART, drug side effects, financial constraints, service related factors, stigma, discrimination, inability to disclose HIV status and a variety of socio-cultural issues (Wasti, S. *et al* 2014**).**

Adolescents and young adults population (10– 24 years) represent above 40 percent of new HIV infections and is characterized occasionally by sexual high-risk behavior and a lack of engagement with healthcare services that can affect adherence to antiretroviral therapy (ART) (Kim et al, 2013). A study conducted in Namibia to diminish non adherence to antiretroviral (ARV) treatment among HIV/ AIDS adult patients, rate of non adherence was 36.7% among 112 adult patients (Chigova,2016).

Variable individual and external factors that can influence adhesion to the use of antiretroviral drugs are variable and it is responsibility of every institution that follows up the patients on antiretroviral drugs to assess if their patients adhere effectively to the ART (Chigova, 2016).

In Gitwe and Ruhango district hospitals in Rwanda, and their catchment area, there are 283 enrolled adolescents HIV positive clients receiving ART and over half of the adolescents among enrolled ones; 81.9% were having poor adherence to ART, 16.3% were having moderate while only 1.8% were having high adherence according to the findings observed in this study.

This survey intended to evaluate adherence level and factors influencing adherence to antiretroviral therapy among HIV positive adolescents attending Gitwe and Ruhango district hospitals' catchment area in Rwanda that can contribute in planning intervention to improve HIV positive adolescent's adherence to ART for quality care and positive outcomes.

1.3. THE AIM OF THE STUDY

The purpose of the study was to assess adherence level and factors influencing adherence to antiretroviral therapy among HIV positive adolescents attending Gitwe and Ruhango district hospitals' catchment area, Rwanda.

1.4. OBJECTIVES OF THE STUDY

1. To assess the level of adherence on antiretroviral therapy among adolescent living with HIV attending HIV service at Gitwe and Ruhango district hospitals' catchment area
2. To determine the factors influencing adherence to antiretroviral therapy among HIV positive adolescents attending HIV service at Gitwe and Ruhango district hospitals' catchment area

1.5. RESEARCH QUESTIONS

1. What is the level of adherence on antiretroviral therapy among HIV positive adolescents attending HIV service at Ruhango and Gitwe district hospitals' catchment area?
2. What are the factors influencing adherence on antiretroviral therapy among HIV positive adolescents attending HIV service at Ruhango and Gitwe district hospitals' catchment area?

1.6. THE SIGNIFICANCE OF THE STUDY

Nursing research

The results from this study will be used as baseline information for further investigations of a similar nature in other settings and conduct big researches across the country.

Nursing practice

The research literature and findings from this study will help nurses to recognize how to deal with adolescents on antiretroviral treatment, and how to help them as health professionals. The findings may also help nurses and other health professionals in ART department to improve their practices, roles, and responsibilities in improving adherence to antiretroviral therapy among adolescents. This study will remind also nurses' standards and guidelines to care for adolescents especially those who live with HIV.

Nursing Education

For educators, the results from this study will help to identify where to emphasize in the curriculum that will help nurse students to handle poor adherence matters especially for those who live with chronic diseases including HIV/AIDS.

Nursing Administration

Results from this survey will be helpful to the authorities at Gitwe and Ruhango District Hospital to take some precautions in the follow up of adolescents taking ARTs and initiate some decisions for improving drug adherence to ARVs among HIV positive adolescents in their catchment area.

1.7. DEFINITION OF KEY TERMS

Poor adherence: is explained as failure for the patient to take the prescribed medication appropriately at least more than 95% of the prescribed drugs (Alloway, 2015**).** In this study poor adherence is defined as the clients receiving ART regimen with less than 95% of the prescribed medication where 81.9% adolescents were having poor adherence to ART, 16.3% were having moderate while only 1.8% were having high adherence according to the findings observed in this study.

Adherence: Good adherence is defined as taking more than 95% of the prescribed medication (Mosha, F. et al 2019).

Antiretroviral therapy (ART)

The everyday use of combined HIV medicines (namely HIV regimen) for treating HIV illness (Lawrence and Flexner, 2017). In this study, antiretroviral therapy refers to the HIV regimen given to adolescents living with HIV.

Adolescent

It is a phase of psychological and physical development from the beginning of puberty to maturity. An adolescent is the person whose age is between 10 and 19 years (divided in early adolescence 10- 14; late adolescence 15- 19 years old) (Jessica L. Morris and Hamid Rushwan, 2015) and according to the Ministry of health in Kenya; adolescent is also the age group between 10 to 19 years old (MOH, 2015). The same for this study, the adolescent is the person whose age is between 10 and 19 years.

1.8. ORGANIZATION OF THE RESEARCH PROJECT

This research project is composed of 6 chapters namely: Chapter one is for introduction, chapter two for literature review, chapter three which is research methodology, chapter four deals with results and interpretation, chapter five deals with discussion and chapter six that highlights conclusion and recommendations.

1.9. CONCLUSION

This chapter described background and problem statement of the study. It highlights also the objectives formulated in response to the research questions. Study significance was also clearly specified and it includes the definition of key terms.

CHAPTER TWO: LITERATURE REVIEW

2.1. INTRODUCTION

This chapter highlights a review of the research literature about the factors influencing adherence to antiretroviral therapy among HIV positive adolescents. The researcher has to indicate what other researchers and scholars revealed out about adherence to antiretroviral therapy, and also the findings observed from the studies conducted by different researchers. This review assist to understand the subject under study and helps to identify gaps for other research and it is composed of theoretical, empirical literature and presents the conceptual framework of the study.

2.2. THEORETICAL LITERATURE

2.2.1 Definition

HIV is a retrovirus that infects mostly the vital organs responsible for human immune system. The virus progresses in the lack of antiretroviral therapy. The rate of virus progression varies extensively between individuals and depends on many factors (body's ability to defend against HIV, access to health care, age of the patient, existence of coexisting diseases, resistance to some strains of HIV, the infected person's genetic inheritance (Shrestha, Altice and Copenhaver, 2019).

HIV is not as infectious as is habitually believed. The virus does not stay alive long outside the body and can be transmitted by direct exchange of definite biological fluids (Bhowmik et al, 2012).

2.2.2 Causes:

Historically HIV/AIDs in humans is caused by tuolenti virus which is HIV types one and two. These HIVs are due to the result of numerous cross-species transmission of simian immunodeficiency viruses (SIVs) that naturally infect the primates. The majority of these transmissions resulted from viruses that may spread in humans to merely a restricted point. Moreover, single transmission occasion concerning SIVcp from chimpanzees in southeastern

Cameroon gave increase to HIV-1 group M-the principal cause of the AIDs pandemic (Sharp and Hahn, 2014).

2.2.3 Mode of transmission:

HIV is likely to enter into the body via the open cuts, breaks and sores in the skin; through mucous membranes, such as those inside the vagina or anus; or during direct injection. There are numerous ways by which this can occur: Sexual contact with an infected person via Vaginal Intercourse, Anal Intercourse, Penile-Oral Sex, Cunnilingus Sex, and Digital-Anal or Digital-Vaginal Sex is the chief mode of transmission of HIV worldwide, needles and syringes sharing, and even other traumatic equipments with an infected person, those children born to HIV positive women can get infected with the HIV virus before or during birth (Mother-to-child transmission), and also during breastfeeding after birth. Although , needle exchange programs, safe sex, treatment to persons who are infected, and circumcision of males are the major methods of prevention of HIV transmission (WHO, 2015).

Even though in the body there is still some HIV, the human immune system is so strong enough to fight off the infection and cancers. Antiretroviral treatment is more recommended to the entire persons suffering from HIV, despite of how long they have had the virus or how healthy they are. HIV will attack the immune system if left untreated and finally progress to AIDS (RBC, 2016).

2.2.4 Risk factors:

Early sexual activity remains an important risk factor for HIV transmission and potentially results in negative health consequences like sexual transmission infection (Bakeera-Kitaka, S., et al 2018).

Adolescents are particularly at high risk for STIs as the result from combination of behavioral, biological and social factors where adolescents are likely to engage in higher risk sexual behaviors such as concurrent partners or without using condoms and adolescents females are more susceptible than adult women to contracting infection if exposed and also adolescents do not likely to pursue STI testing due to confidentiality concerns even stigma contribute to reduced screening uptake (Shannon, C.L., et al 2019).

2.2.5 Management of HIV:

Combined antiretroviral drugs are used to fight against HIV infection. Antiretroviral therapy is not appropriate cure, although it may reduce the viral load hence the person may survive a longer, better living as well as reducing the transmission hazard of HIV to the people (Folkers, 2012).

Antiretroviral therapy involves taking of combined medicines against HIV known as an HIV treatment regimen that should be taken daily and accurately as prescribed. These HIV drugs have goals of suppressing the viral load to untraceable, elevation of CD4 cells count which improves immune reconstitution, decrease of HIV transmission, lessen cross resistance risks, reduce also long term toxicity and improve the clinical outcomes of clients, minimize a health care cost, improve the welfare of the clients, help to achieve growth and development (Folkers, 2012).

Non-adherence is one of the most significant challenges to the successful management of HIV-infected individuals, especially adolescents. It may be due to any combination of structural, provider-related, patient-related, disease-related, medication-related and psychological barriers. Adherence is not constant and necessitates to be reviewed usually as the factors predisposing to non-adherence and this may change over time, hence requiring variety approaches to address them appropriately. Similarly to the HIV infected adolescents from different settings like resource rich and resource limited experience different difficulties to adherence in those settings (Wasti, et al, 2012).

Adherence is found to be one of the most challenges in adolescents suffering from HIV that experience unique barriers to this specific age group and also their living conditions.

Believes, perception and unintended disclosure of HIV status hindered adolescent people from obtaining and taking their medicines, attendance during the visits of clinics, carrying their antiretroviral drugs with them in the public. Life style like orphanage, further care, and even adolescent boarding at schools have shown a significant effect to ART adherence and thus some precautions have to be done in order to deal with stigma, privacy barriers, social support constraints and improve accessibility to the medication to every situation (Mutwa *et al.*, 2013).

In particular, the results recommend that mental health must be considered among the factors associated with ART non adherence in HIV departments for youth, mainly for mental health

outcomes, like behavioral problems and depression, staff attitudes and relationship to the patients play other role to non adherence to ART (Fawzi *et al.*, 2016).

It is also advisable to put in place some specific measures to help the adolescent adhering to medication like disclosure, counseling to minimize trauma/loss and treatment of concurrent psycho-diagnosis (like anxiety, substance abuse and depression), information on HIV and advantages of ART. In clinical practice, some adolescents accept the use of reminder system such as alarm clocks which is useful method for treatment adherence (Agwu and Fairlie, 2013).

In 2016, The Government of Rwanda decided to initiate ART to all people tested HIV positive without considering their clinical or immunological status. This approach increased the number of client consulting health facility, availability of ART and treatment for opportunistic infections including qualified health personnel in ART services. Therapeutic efficacy of ART necessitates an adherence of more than 95% (MoH, 2016) and the health personnel should evaluate adherence at every visit especially at the pharmacy, medical consultation, social and nutritional services. The following factors have important role in the adherence to antiretroviral therapy: factors related to treatment, and attitude of the client towards to medication, socio-economic resources and environment, follow-up and care provided at the health facility. The second line of ART is indicated if the viral load is greater than 1000 copies/mm^3 for 6 months after appropriate initiation of ART for the first line regimen (MoH, 2016 p. 27). The clients receiving ART first line regimen with two successive viral load check up should demonstrate viral suppression of lesser than 200 copies of RNA/mm^3 and if the results reveal that there is elevation of viral load instead of reduction, it is an indicator of non adherence to ART regimen prescribed to the client. The third line is also indicated to the clients under ART with the viral load more than 100 copies/ml at 6 months from initiation for the second line regimen. (MoH, 2018 pp. 11)

According to UNAIDS, knowledge about the infection related to HIV helps to improve the engagement in provision of care and antiretroviral initiation that leads to the reduction of HIV virus in the body which is also called HIV continuum of care). Recently, it has introduced a target of 90-90-90 by 2020 for the continuum care where 90% of HIV positive people will be aware of their HIV status, 90% of HIV positive people who know their status will be receiving

ART, and 90% of individuals on ART will be having virological suppression (Ruanne V Barnabas and Connie Celum, 2015).

2.2.6 Types of failures during the management of HIV:

Poor adherence to ARV leads to the treatment failure and 3 kinds of the treatment failure exist including virology failure, immunologic failure and clinical progression. Virology failure occurs when ARV drugs do not decrease the amount of virus in the blood stream. While taking medications, viral load doesn't drop or it repeatedly rises again after having dropped and immunologic failure happens when the immune system doesn't respond to ARV medications and CD4 count doesn't rise or it drops while taking medications, the clinical progression happens when a person has symptoms of HIV diseases despite taking ARV medications (Hinkin et al 2014).

2.2.7 Side effects from ART:

There are some potential risks related to ART including side effects from HIV drugs and medicine interaction between HIV medications and other treatments that a person is receiving. Poor adherence, not taking HIV drugs daily and appropriately as prescribed, those elevate the possibility of drug resistance and treatment failure. Side effects resulted from HIV treatment can vary depending on the drugs and the person taking the treatment. Persons receiving the same HIV medicine may have very different side effects. Some side effects, like occasional dizziness or headache, may not be serious. Other side effects, such as enlargement of the throat and tongue or liver damage, considered to be life-threatening (Jennifer, 2014).

2.3. EMPIRICAL LITERATURE

2.3.1 Adherence on antiretroviral therapy among adolescents living with HIV.

Caregivers play a great role in adherence to medication for children. In a study aimed to explain the caregiver factors related with adherence to antiretroviral therapy among children at Thika District hospital in Kenya on a sample consisted of 200 caregivers with a response rate of 93%, 57.5% (115) of admitted caregivers due to missed dose of at least one medication in the previous 24 hours that put the estimated rate of non adherence at 57.5%. The lowest percentages of adherence were observed in caregivers 20 years of age and below 32% and those above 60 years

(31%). From caregivers' perspectives, they also highlighted that they were incapable to attain optimal adherence (taking <95% of the doses of the combination every week) and less than 95% adherence rate was related with virology failure of 75% and also increases the risk of medication resistance (Akinki, 2011). Consistently, a study conducted in UGANDA, out of 1824 adolescents, the majority 90.4% had good adherence ≥ 95%. Mostly setting in rural health facilities was autonomously linked with poor adherence to antiretroviral therapy (p=0.008, OR=2.64) and stigma, discrimination, disclosure issues, poverty, fatigue, side effects, pill burden and depression were the barriers to adherence (Barungi *et al.*, 2015).

On the other hand, caregivers'' knowledge about antiretroviral therapy, no current use of substances, close proximity to health facilities and letting child's know his/her HIV status has been evidenced to factors that improves adherence to antiretroviral therapy (Tessema and Kassa, 2014).

From the quantitative analysis of a study factors influencing antiretroviral treatment suboptimal adherence among prenatally HIV-infected adolescents in Thailand on a total of 275 (48.4%) adolescents had evidenced suboptimal adherence due to the missing doses in the past 7 days and also the caregiver rating of overall adherence as suboptimal, or latest HIV-RNA viral load ≥1000 copies/ml (Xu Luyi *et al.*, 2017 p 1-2).

2.3.2 Factors related to adherence on antiretroviral therapy among adolescents living with HIV.

In the qualitative approaches in the study to determine the factors influencing adherence among prenatally infected adolescent in Thailand by Xu Luyi *et al.*, (2017), younger age that have grandparents or extended family members as the primary caregivers and also the caregiver assessed poor intellectual ability, having a boy/girlfriend, self-reported unhappiness, frequent online chatting and easiness in asking doctors questions were significantly related with suboptimal adherence. Furthermore, forgetfulness due to busy schedules, relationships with caregivers and fear of disclosing HIV status to others, particularly boy/girlfriends were significant contributors to suboptimal adherence (Xu Luyi *et al.*, 2017).

Another study done in Uganda revealed that feeling improved after same drug period, alcohol consumption, being too ill to take medication, stigma linked with taking ART medicine and

medication stock out have been also recognized as associated with non adherence (Buyu et al., 2016).

The challenges associated to poor adherence have organized in around the social barriers, therapy-related barriers, health team and system barriers, patient-related barriers, economic barriers and cultural barriers. From individuals stigma, unemployment, disclosure, insufficient feeding, lack of transport, disability grants alternative forms of therapy were identified as major barriers to adherence, whereas inadequate follow up and lack of patient confidentiality came under major criticisms from the patient (Azia et al, 2016).

Further study in the systematic review of 15 studies assessing correlates and predictors of ART adherence representing 4363 participants across 10 LMICs, categorized factors associated with adherence into four broad themes related to the (1) adolescent, (2) medication (3) caregiver, and (4) social, physical, and/or healthcare environment. In this study general potential factors crossways studies, including the possible impact of (1) the influence of family structure, (2) gender and knowledge of serostatus, (3) the impact of burdensome ART regimens, route of administration, and attitudes about medication, and (4) health care and environmental factors, such as rural versus urban location and having missed clinic appointments (Hudelson and Cluver, 2015).

Poor adherence on ART has been associated with orphan category and in the study done in Rwanda on high risk ART non adherence and delay of ART initiation among HIV positive Double Orphans in Kigali, of all children (N= 717) respondents from every orphan category (double orphan, maternal orphan, paternal orphan, non-orphans) ART poor adherence rate of each orphan category was 59.3%, 44.9%,46.7% and 49.7% respectively that show that double orphans were at highest risk of ART non-adherence and especially those who had a sibling as a caregiver had high risk (Mukui *et al.*, 2016).

Further study on HIV-infected adolescents have low adherence to antiretroviral therapy in Addis Ababa, Ethiopia marital and living status of the parent, whether parent was on ART or not and having special instructions for ART medications were associated with optimum adherence and adolescents with widowed parent (adjusted OR, 0.087 with 95% CI, 0.021-0.359) were found to be significantly associated with optimum ART adherence (Firdu et al, 2017).

In the paper described baseline findings from a cohort of 242 Malaysian adolescents receiving ART within the context of an intervention aimed to improve adherence and treatment outcomes among patients initiating ART, males accounted for about 90% of those initiating ART in the HIV clinic, at a relatively low CD4 count, high viral load and sub-optimal medication adherence levels at baseline (Abiola *et al.*, 2015).

In the qualitative study on living situation affects adherence to combination antiretroviral therapy in HIV-infected adolescents in Rwanda showed that lack of privacy to keep and take medication came out as major barrier for adolescents living in congested households, as well the institutionalization of boarding schools where privacy is almost non-existent (Mutwa et al., 2013).

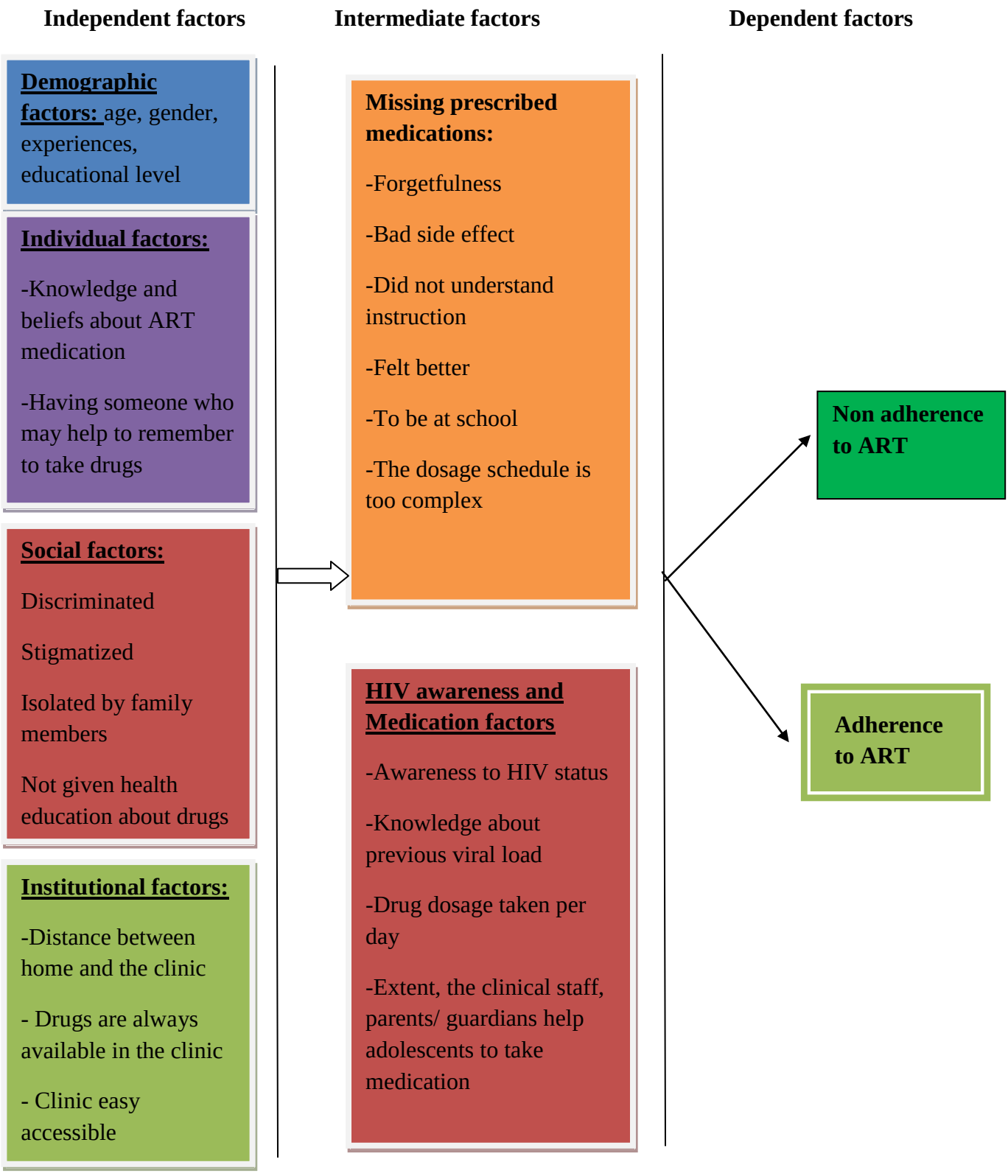
2.4 CRITICAL REVIEW AND RESEARCH GAP IDENTIFICATION

Reviewed literatures have shown different level of no adherence to antiretroviral therapy among adolescents in various countries. However, most literature reviews are quantitative than qualitative and also mixed methods are more needed to extend for further factors.

2.5. CONCEPTUAL FRAMEWORK

A conceptual frame work arguments the study in relevant knowledge bases that put the foundation of the significance to the problem statement and research questions (Nkurumah and Hussein, 2018).The conceptual framework helps to guide the literature review and the accomplishment of the research. The model constitute the interaction of patient associated factors to health system, related factors and providers factors to influence the adherence behaviors of patients (Abdissa, 2013).

In view of these interactions the researcher will adapt a conceptual framework developed by Grenard et al, (2009) for reviewing barriers to medication adherence as illustrated in below the diagram.



Barriers to medication adherence conceptual framework adapted from Grenard et al, 2009.

CONCEPTS OF THE FRAME WORK:

Individual factors: These are the factors related to the adolescents that describe socio-demographic information and knowledge of adolescents concerning to the ART.

HIV awareness and medication factors: described how adolescents were aware of their HIV status and how the clinical staff, parents/ guardians help them to take medication and these factors may influence good adherence to ART.

Social factors: These factors describe if the adolescents were miss managed by the family members/ friends and how they managed them negatively hence affecting the adherence to ART.

Institutional factors: These factors determine the distance to be covered from home to the clinic, availability of drugs at the clinic which may have influence to the adherence.

Missing the prescribed medication: showed the reasons for not taking the drugs appropriately which had impact on the adherence.

CONCLUSION

The literature review for this study shows that poor adherence is still a challenge across countries and the challenges associated to non adherence are grouped into individual, social and organizational factors. From individuals of younger age, forgetfulness due to busy schedules, the relationships with caregivers and even fear of disclosure of her/his HIV status to other people, mainly boy or girl friends, alcohol consumption, feeling well and drug stock out were important to individual factors influencing non adherence.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1. INTRODUCTION

Research methodology is a method to scientifically solve the research problem. It may be understood as a science of studying how research is done systematically (Iguenagu,2016).
This chapter highlights the different methods that have been used throughout the progression of the study. It includes the study setting, study design, the research approach, study population and sample size as well as the sampling strategy that had been also used. It illustrates also the information about data collection procedures and data analysis, data management; dissemination and ends with ethical considerations that were used.

3.2 RESEARCH APPROACH

A quantitative approach was used in this study. This is an approach from which everything that forms the research process; objectives, design, sample, and the questions that you plan to ask of respondents are predetermined here, the researcher want to quantify the variation in a phenomenon, situation, problem or issue; if information is gathered using predominantly quantitative variables; and if the analysis is geared to ascertain the magnitude of the variation (Grover, 2015).

3.3 RESEARCH DESIGN

Research design is the process that guide researchers on how to collect, analyze and interpret observation and it is a logical model that guide the investigators through various stages of research (Getu, 2016).

This study has used a non experimental descriptive cross-sectional design. Descriptive study attempts to illustrate scientifically the situation or problem, phenomenon, service or program, and provides information related to the living circumstances of a community, or describes attitudes towards an issue (Grover, 2015). Cross-sectional studies, also called as one-shot or status studies are the most frequently used design in the social sciences. This design is best suitable to studies aimed at finding out the prevalence of a phenomenon, condition, problem,

attitude or issue, by taking a cross-section of the population. They are helpful in obtaining an overall 'picture' as it stands at the moment of the study (Kumar, 2011). In this study the data was collected in one point of time to assess the adherence to antiretroviral therapy among adolescents living with HIV.

3.4. STUDY SETTING

The research setting can be seen as the social, physical, and cultural position in which the researcher conducts the study (Iguenagu, 2016).

The study was conducted at Gitwe and Ruhango District hospitals' catchment area, located in southern province, Ruhango District, where Gitwe hospital if found in Bweramana Sector, Murama Cell in Karambo Village. It is located near the road that comes from Buhanda market to Nyanza town just near Bienvenue center. It was chosen because the researcher observed poor adherence among HIV+ adolescents in ART department during clinical practice at this site and the researcher was inspired to rule out the factors influencing non adherence to ART among HIV positive adolescents in the same area.

Regarding its infrastructures, the hospital has three buildings made of four flows, one building also made up of two flows and three buildings made of one flow. It serves a population of 158505 people found in the sectors respective to health centers in the catchment area of hospital. (Gitwe hospital strategic plan 2013- 2018)

Ruhango District has two district hospitals namely Gitwe district hospital and Ruhango district hospital but the researcher has collected data from Gitwe and Ruhango district hospitals and their catchment area.

Gitwe District hospital started working on 25th September 1981 as a private hospital created by APAG (Association des parents Adventististes de Gitwe) where it began its activities with only one Doctor and four Nurses. Since 2001, Gitwe Hospital has been considered as a District's Hospital and it has had the responsibilities of supervising all of health center in its catchment area which were located in Ruhango District. Those health centers are Gitwe, Karambi, Muyunzwe, Muremure, Gishweru, Byimana and Mwendo which were also engaged in heath promotion, prevention of illness and also restorative services at the primary level. Concerned

with the health care services nowadays provided by Gitwe District hospital is grouped in four departments namely outpatient department (OPD), inpatient departments, emergency and trauma departments and clinical support services.

Every department has separated into purposeful units as well as: ambulatory/ outpatient services where departments are: common OPD, physiotherapy department, ophthalmology department, Stomatology department, mental health department, VCT, PMTCT and ARTs services. Inpatient departments are: gynecology/obstetrics department, neonatology department Pediatric department, Internal medicine, surgery and theater departments. Emergency: emergency care unit, ambulance, minor surgery and GBV. Clinical support units: open MRS for registration and medical record filing, laboratory, medical imaging department like radiography, ultrasound, and others namely also; pharmacy, accountancy, nutrition and rehabilitation services and also Laundry. (Gitwe district hospital administrative manual 2017)

The researcher has collected data from Gitwe hospital as described above and these health centers; Gitwe health center (H/C) located in Bweramana sector that serves primary health care services to 32879 people in its catchment area, Karambi H/C and Munanira H/C are located in Kabagali sector and provide primary health care services to 14980 people and 12371 people respectively in their catchment area, Byimana H/C located in Byimana sector and serves primary health care services to 39345 people in its catchment area, Muyunzwe H/C and Muremure H/C are located in Kinihira sector and serve primary health care services to17968 people and 11240 people respectively in their catchment areas, Mwendo H/C and Gishweru H/C are located in Mwendo sector and serve primary health care services to 14494 people and 15229 people respectively in their catchment areas (Gitwe DH report April, 2018).

The researcher has also collected data from Ruhango District hospital located in Kinazi sector which is a government institution started on 28 may 2012 that serves 212945 people currently in 2018 found in 4 sectors namely Mbuye, Kinazi, Ntongwe, Ruhango, and Mukoma sector. It serves also 7 Health Centers with their respective population for each which are: Kinazi (29283), Mukoma (20411), Nyarurama (37029), Mbyuye (27260), Kigoma (27324), Kizibere (20114) and Ruhango HC (47901) (Ruhango district hospital administrative manual, 2018).

3.5. STUDY POPULATION

A complete set of elements (persons or objects) that possess some common characteristic defined by the sampling criteria established by the researcher (Iguenagu, 2016).

3.5.1. Target population

Target population refers to the whole group of individuals or objects to which researchers are concerned in generalizing the conclusions. The target population generally has varying characteristics and it is also called as the theoretical population (Grover, 2015)

The target population for this study is HIV positive adolescents (10-19 years old) on antiretroviral therapy in Gitwe and Ruhango district hospitals' catchment area.

3.5.2. Accessible population

The sample of the population to which the researcher has reasonable access; may be a subset of the target population (Almec, 2015)

The accessible population for this study is HIV positive adolescents (10-19 years old) with 3 months on antiretroviral therapy in Gitwe and Ruhango district hospitals' catchment area. The data was collected from Gitwe and Ruhango district hospital and 15 Health centers with the total of 283 adolescents enrolled in the treatment of HIV (Gitwe DH report August, 2018) (Ruhango DH report August, 2018).

3.6. SAMPLING

3.6.1. Sample size

Table3 1HIV positive adolescents enrolled in gitwe district hospital's catchment area and who are currently on art.

Health Facility	**August 2018**
Byimana H/C	19
Gishweru H/C	2
Gitwe H/C	6
Gitwe DH	50
Karambi (Ruhango) H/C	8
Munanira H/C	1
Muremure H/C	7
Muyunzwe H/C	26
Mwendo (Gitwe) H/C	5
Total	**124**

(Gitwe DH report August, 2018)

Table3 2 HIV positive adolescents enrolled in Ruhango district hospital's catchment area and who are currently on ART

Health Facility	**August 2018**
Ruhango DH	02
Kinazi H/C	22
Mbyuye H/C	18
Mukoma HC	5
Nyarurama H/C	12
Kigoma H/C	23
Kizibere H/C	24
Ruhango H/C	53
Total	**159**

(Ruhango DH report August, 2018)

The sample size for this study was obtained using the formula given by Taro Yamane 1967 as the following:

$$n = \frac{N}{1+N(e^2)}$$

Therefore n: is the sample size

N: is the total population

e: is the marginal error set at 95%= 0.05

$$n = \frac{283}{1 + 283*(0.05)^2}$$

Then, n= 166 adolescents

3.6.2. Sampling strategy

The process of selecting a group of people, events, behaviors, or other elements with which to conduct a study (Almec, 2015).

Proportionate stratified random sampling technique was applied to select 166 samples of adolescents. Here the researcher formed 17 strata according to the health facilities of Ruhango and Gitwe catchment area that includes of 2 district hospitals and 15 health centers and here the researcher by simple proportion calculation (n=population in stratum*sample size/whole population) was used to find the sample size of each stratum then after, simple random sampling was applied in each stratum. Here the researcher has taken the list of adolescents in each stratum and gave code each name then after picked randomly the code until the sample in stratum is found. Therefore, the sum of samples of strata was 166 adolescents, a sample of the study as summarized in the below table:

Table3 3Sample size of HIV positive adolescents enrolled in Gitwe district hospital catchment area to be selected in the study.

Health Facility	**Population**	**Sample size**
Byimana H/C	19	11
Gishweru H/C	2	1
Gitwe H/C	6	4
Gitwe DH	50	30
Karambi (Ruhango) H/C	8	5
Munanira H/C	1	1
Muremure H/C	7	4
Muyunzwe H/C	26	15
Mwendo (Gitwe) H/C	5	3
Total	**124**	**74**

Table3 4Sample size of HIV positive adolescents enrolled in Ruhango district hospital catchment area to be selected in the study

Health Facility	Population	Sample size
Ruhango DH	2	1
Kinazi H/C	22	13
Mbyuye H/C	18	11
Mukoma HC	5	2
Nyarurama H/C	12	7
Kigoma H/C	23	13
Kizibere H/C	24	14
Ruhango H/C	53	31
Total	**159**	**93**

3.6.3. Sampling criteria

3.6.3.1. Inclusion criteria

Adolescents of any gender living with HIV either acquired perinatally or not, who were receiving antiretroviral therapy for 3 months and who are aged from 10 to 19 years and who accepted to participate in the study were included in this study.

3.6.3.2. Exclusion criteria

- Adolescents who were on ART with less than 3 months on treatment
- Adolescents who were above 19 years old
- HIV+ adolescents who were not registered in the selected district hospitals' catchment area.
- Adolescents who were not taking antiretroviral drugs.

3.7. DATA COLLECTION TOOLS AND PROCEDURES

3.7.1. Data collection instruments

Adapting the instrument:

In this research, a questionnaire with close ended questions was adapted from the study conducted in Kenya by Nziva Musembi (2013) on factors influencing adherence to antiretroviral therapy at Mbagathi district hospital, Nairobi.

In this study, the sample size was 85 clients who were already registered and initiated on the therapy. Some of the factors affecting adherence to ART that were highlighted in this study were complex dosage, bad side effects, negative reactions from the family members and mentioned the adequate knowledge to HIV infection and availability of drugs in health facilities as factors influencing adherence to ART.

This tool has the following parts:

Items	**Independent variables**	**Dependent variables**
Part I: Socio-demographic data	Gender, age, education level	Adherence and
Part II: Adherence level	Awareness of HIV status, knowledge about previous viral load, some medication factors.	Non adherence
Part III: Factors influencing adherence to ART	Client factors: how ART drugs are compared with other medications, reasons for missing/not missing drugs. Health care provider factors: judgmental attitude of health care provider…, Institutional factors: long distance from home to the clinic, insufficient health care providers and accessibility of ART in the health facilities.	

3.7.2. Validity of the tool

The term validity refers to whether the test measures what it claims to measure and is the one of the methods to ensure validity of the tool, the questionnaire was given to experts in HIV management to be reviewed if it measure what it intended to measure (Kumar, 2015).

3.7.3. Content validity

According to Khandoker (2016), Face validity is a subjective judgment of whether measures of certain construct "appears" to measure what it intend to measure.

Also, the content validity was used for this study and this method indicated how the research questions were answering to the research objectives.

Face validity:

This tool was given to the experts in clinical setting and academic environment to review it.

Table3 5Content validity of the data collection

Objectives	**Conceptual variables**	**Questions**
1. To assess the level of adherence on antiretroviral therapy among adolescent living with HIV attending HIV service at Gitwe and Ruhango district hospital's catchment area	Awareness to HIV status Knowledge about the previous viral load Drug dosage per day Extent clinical staff, parents/ guardians help the adolescents to take medication.	**PART II: Q4 to Q9**
2. To determine the factors related to non adherence on antiretroviral therapy among adolescent living with HIV attending HIV service at Gitwe district hospital	**<u>Individual factors:</u>** -Socio-demographic factors: (age, gender, experiences, educational level) -Beliefs about ART medication - Forgetfulness	**PART 1: Q1 to Q3** **PART III: Q10 to Q3**
	<u>Social factors:</u> Number of pills Discriminated Stigmatized	**PART I: Q5 to 6** **PART III: Q14**

	Isolated by family members	
	Organizational factors: - Drugs are always available in the clinic - Clinic easy accessible -Cost -Drug stock out	**PART III: Q15 -Q17**
	Missing prescribed medications: -Forgetfulness -Bad side effect -Did not understand instruction -Felt better -To be at school -The dosage schedule is too complex	**Part III: Q12**

3.7.4. Reliability of the tool

Reliability refers to the degree to which the results obtained by a measurement and procedure can be replicated (Oladimeji, 2015).

3.7.4.1 Pretesting:

To ensure reliability a pilot study has been conducted on 16 adolescents and Cronbach's alpha for internal consistence reliability was computed. The coefficient Cronbach's alpha equal to 0.792 an acceptable value for reliability of the tool was found. Bruin (2006) showed that the acceptable minimum value for Cronbach's alpha is 0.70; below this value the internal consistency of the common range is low. Meanwhile, the maximum expected value is 0.90; above this value is perceived as redundancy or duplication.

3.7.4.2 Translation of the tool:

The tool was in English and was translated in Kinyarwanda for easing the understanding of it by the participants.

3.7.4.3 Permission to use the tool:

This tool was adopted after receiving the permission to adjust it (Annex No 4).

3.7.5. Data collection procedure

For data collection of this study, the investigator obtained the signed consent and assent forms for those who accepted to participate and explained about the aim of the study and even how to fill the questionnaire to the adolescents. Then later, the investigator had distributed the questionnaire to the adolescents to fill themselves in those who were able to read. As the respondents were requested to choose the version of their choice, the investigator was also available to give any assistance where possible and to read for those who were unable to read and record their responses. Data collection was done in five days a week, especially in morning hours from 8:00 AM to 4:00 PM for a period of 6 weeks.

3.8. DATA ANALYSIS

Data entry and coding were done using SPSS version 23. Descriptive statistics (frequency, mean, and standard deviation) have been used to analyze continuous or categorical variables mostly and inferential statistics using Chi. square tests and multiple regressions analysis were used to associate the factors influencing non adherence to ART to those HIV+ adolescents. ART adherence was defined as taking more than 95% of the prescribed treatment 3 months prior to the completion of the questionnaire. ART adherence was self-reported. The significant level was set at 95% CI; p-value of 0.05. Data analysis was done using both descriptive and inferential statistics with CI set at 95% and p-value >0.05.

3.9. ETHICAL CONSIDERATIONS

3.9.1 Ethical approval

In accordance with ethical principles guiding research involving human subjects, this study has been conducted after obtaining approval from the Institutional Review Board (IRB) from University of Rwanda.

Permission to collect data was also obtained from Gitwe and Ruhango district hospitals.

3.9.2 Informed consent and assent process

As specified earlier, participation was voluntary; no form of compulsion has been exercised and adolescents had the right to withdraw from the study willingly. As the participant of the study was children between 10-19 years old, those who were under 18 years old the participation was voluntary after their consent signature and from their parent or guardian and they had also signed an assent form. Those who were between 18-19 years they signed the consent themselves. The consent and assent have been in a written form with details on ethical considerations and procedure of the study, benefits, confidentiality, risks and the right not to participate or withdraw at any time. The researcher was there to help participants who have reported any difficulties in filling of the questionnaire or any question relating to the study.

3.9.3 Confidentiality:

Confidentiality of the data was maintained as the data was not availed to any person not concerned in the study. To ensure confidentiality no name of participant was recorded on questionnaire. The researcher was guided by the ethical principles during data collection. These were: beneficence, justice, respect of people, and these ethical principles were also based on human rights that have been protected by researcher like privacy, anonymity and confidentiality.

Anonymity: This was violated because the researcher was available during data collection and the adolescents were reassured that all information provided will be protected appropriately.

3.9.4 Risks:

There were no predictable physical risks in participating in this study but there were psychological and emotional risks where the adolescents received counseling that the information provided will be kept safely and nobody shall access it without permission.

3.9.5 Benefits:

There was no immediate or direct benefit to the respondents although the information that was gathered from the study, might create awareness to the health authorities, health care providers, adolescents and their families about the significance of maintaining the recommended ART adherence level of or above 95% and factor that could likely result to low level of adherence.

3.9.6. Participant rights protection:

Autonomy: The participation in the study was completely voluntary.

Self withdrawn: The researcher had explained the aim of the study and described to the participants that they had the right to withdraw from the study at any time.

Right to privacy: The participants were reassured before answering the questionnaire that information provided will not be shared without permission.

Self determination: Participants were having the right to decide whether or not to participate without penalty for failing to take part in the study and were allowed ask questions and get answers related to the study from the researcher.

3.9.7. Costs:

There were no costs associated with participating in the study.

3.10. DATA MANAGEMENT

Obtained hard data are stored in locked cupboard and soft data is stored in secured lap top in the database locked by password and data are valid for 5 years; after those five years, data will be destroyed.

3.11. DISSEMINATION OF FINDINGS

The findings will be disseminated firstly by presentation at Gitwe and Ruhango District hospitals with their 15 health centers and the University of Rwanda and secondly through seminars, workshops and publication journals under the permission of the institution where the study was conducted.

3.12. LIMITATION AND CHALLENGES OF THE STUDY

This study had some limitations, mainly related to the fact that the sample which was used in this study was selected from a single district and therefore making it hard for the results to be generalizable to all HIV positive adolescents on antiretroviral therapy in other district health facilities in Rwanda.

3.13. CONCLUSION TO THE CHAPTER THREE

Chapter three of this study showed that the study was a descriptive cross sectional study conducted at Gitwe and Ruhango district hospitals' catchment area with 283 adolescents receiving antiretroviral therapy in 15 health centers, two district hospitals and stratified random sampling was used to examine 166 adolescents from the entire population. To collect data; self administered questionnaire was used and data entry and coding was also done using SPSS version 21. Data analysis has been done using both descriptive and inferential statistics with CI set at 95% and p-value >0.05 as this study regarded to human subject, ethical consideration was respected and obtained information is kept in secured manner.

CHAP IV: RESULTS AND INTERPRETATION

4.0 INTRODUCTION

This Chapter describes the results of the study. All data variable were quantitative and descriptive statistics using frequencies and inferential statistics chi-square, multiple regression analysis were applied to find out the association of variables. The results were interpreted and presented using tables and pie-chart. The results of the study are presented according to the objectives of the study.

4.1. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE ADOLESCENTS.

Table 4.1 below shows that the majority of participants 33(19.9%) were from Gitwe hospital followed by Ruhango health center 30(18.07%). And minority of participants was at Munanira health center and Gishweru health center 1(0.6%).

Table4 1Distribution of adolescents according to their facilities

Health facility	**Frequency**	**Percent**
Gitwe Hospital	33	19.9
Muremure health center	4	2.4
Gitwe Health Center	4	2.4
Munanira Health Center	1	0.6
Munyunzwe Health Center	15	9.0
Karambi Health Center	5	3.0
Mwendo Health Center	3	1.8
Gishweru Health Center	1	.6
Byimana Health Center	11	6.6
Kigoma Health Center	14	8.4
Nyarurama Health Center	7	4.2
Mbuye Health Center	11	6.6
Kinazi Health Center	10	6.0
Kizebere Health Center	14	8.4
Ruhango Hospital	1	.6
Ruhango Health Center	30	18.07
Mukoma Health Center	2	1.2
Total	**166**	**100.0**

Table 4.2 below shows that the majority of participants 89(54%) were female and 77(46%) were male. The age of participants, 86(51.8%) were between 10-14 years old while 13(7.8) were 19 years old. The majority of participants 142(85.5%) were still studying, 8(5.7%) were in boarding school.

Table4 2Distribution of participants according to social demographic data

Variables	Frequency	Percent
Age (n=166)		
10-14 years old	86	51.8
15-18 years old	67	40.4
19 years old	13	7.8
Gender (n=166)		
Male	77	46
Female	89	54
Adolescents who are studying (n=166)		
YES	142	85.5
NO	24	14.5
Adolescents who are in boarding school (n=142)		
YES NO	8 134	5.7 94.3

This figure below shows that the majority of participants 89(54%) were female and minority 77(46%) were male.

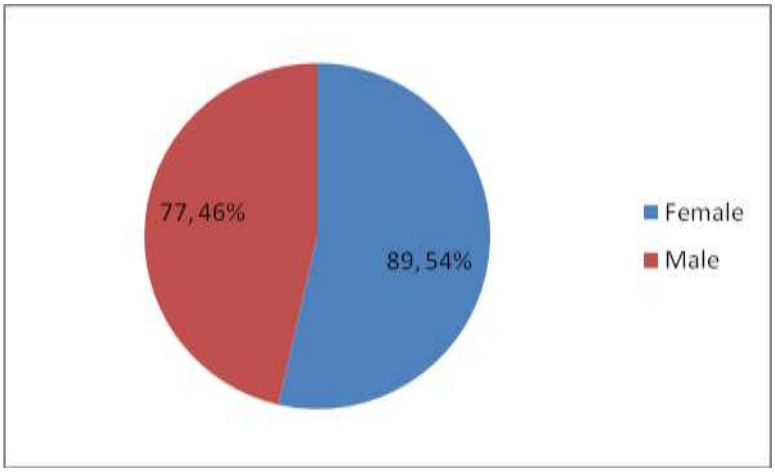


Figure 4.1: Distribution of participants according to gender

4.2 ADOLESCENTS' ADHERENCE LEVEL TO ART AND MEDICATION FACTORS

Table 4.3 below shows that 163(98.2%) were aware of their HIV status. This table revealed also that almost of respondents 162(97.6%) knew about their previous viral load, 4(2.4%) did not know their previous viral load and from those who knew their previous viral load, 98(60.5%) were below 200/mm^3 means that adhered to the treatment while 64(39.5%) were over 200/mm^3 that means non-adherence to antiretroviral treatment.

This table also shows that the majority of adolescents 94(56.6%) take drugs twice per day majority also 138(83.1%) they take below 5 pills per day and minority 2(1.2%) take drugs between 11-15 pills per day and demonstrates that the majority of participants 109(65.7%) were reminded by staff to take drugs a lot and minority 3(1.8%) are not reminded by staff and The 133(80.1%) be reminded by parent or guardian to take medication.

Table4 3Adolescents' adherence level to ART and medication factors

Distribution of adolescents according to HIV status awareness (n=166)			
YES	163		98.2
NO	3		1.8
Adolescents who know their previous viral load (n=166)			
YES	162		97.6
No	4		2.4
Distribution of adolescents according to their viral load (n=162)			
<200/mm^3	98		60.5
>200/mm^3	64		39.5
Frequency of taking drugs in a day (n=166)			
Once per day	Yes	72	43.4
	No	94	56.6
Twice per day	Yes	94	56.6
	No	69	41.6
Quantity of pills taken in a day (n=166)			
Below 5 pills per day	Yes	138	83.1
	No	28	16.9
Between 6-10 pills per day	Yes	26	15.7
	No	140	84.3
Between 11-15 pills per day	Yes	2	1.2
	No	164	98.8
The extent the parent/ guardian/ family members help to remember to take medication.			
Not at all	1		0.6
Sometimes	32		19.3
A lot	133		80.1
The extent does the clinic staff (nurses, doctors, counselors) help you remember to take your medication.			
Not at all	3		1.8
Sometimes	54		32.5
A lot	109		65.7

Table 4.4 below shows that the majority of the adolescents 136(81.9%) were having poor adherence to ART, 27(16.3%) were having moderate while minority 3(1.8%) were having high adherence.

Table4 4 Adherence score to ART (n=166)

Score (10)	Adherence level (%)	Frequency (%)	Level of adherence	Measure of Central Tendency	Value
4	40	1(0.6)	Poor adherence	Mean Median Mode Std. Deviation Variance Range Minimum Maximum	7.8253 8.0000 8.00 0.92091 0.848 6.00 4.00 10.00
5	50	2(1.2)			
6	60	10(6.0)			
7	70	32(19.3)			
8	80	91(54.8)			
9	90	27(16.3)	Moderate adherence		
10	100	3(1.8)	High adherence		

Table 4.5 below reveals that there was no significant association between socio-demographic data and level of adherence.

Table4 5 Association between socio-demographic data and level of adherence cross tabulation

Variable	Test	Value	df	P.value
Gender*level of adherence	Pearson Chi-square	6.173	6	0.404
Age*level of adherence	Pearson Chi-square	20.474	12	0.059
Are you still studying*level of adherence	Pearson Chi-square	3.672	6	0.721
If yes, are you in boarding school*level of adherence	Pearson Chi-square	4.402	5	0.493
Are you aware of your HIV status*level of adherence	Pearson Chi-square	1.687	6	0.946

Table 4.6 below shows a significant association between medication factors and level of adherence where taking drugs twice per day has a *p=0.037*, the extent to which the clinical staffs help the adolescents to take medication has a *p=0.000* and the extent to which the parents/guardians help the adolescents to take medication has also a *p=0.000.*

Table4 6 Association between medication factors and level of adherence cross tabulation

Variable	**Test**	**Value**	**df**	**P.value**
Number of dosages per day				
Once per day*level of adherence	Pearson Chi-square	10.200	6	0.116
Twice per day *level of adherence	Pearson Chi-square	13.376	6	0.037
How many pills do you take in a day*level of adherence	Pearson Chi-square	3.448	12	0.991
To what extent does the clinical staff help you to remember to take drugs*level of adherence	Pearson Chi-square	241.613	12	0.000
To what extent do your parents/guardians help you to remember to take drugs *level of adherence	Pearson Chi-square	245.252	12	0.000

4.3. FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY:

4.3.1. Client Factors

According to the following Table 4.7, the majority of adolescents 103(62%) stated that they see ART drugs as good and they do not get many other illnesses when they take them consistently, and followed by 128 (77.1%) who declared that they feel better whenever they take them.

Table4 7Adolescents' opinion about ART compared to other drugs (n=166).

Variables	Frequency		Percent
Adolescents' opinion about ART compared to other drugs			
They are good, I always feel better whenever I take them	Yes	128	77.1
	No	38	22.9
I would rather go for prayers or herbs instead	Yes	6	3.6
	No	160	96.4
I do not get any change whenever I take them	Yes	30	18.1
	No	136	81.9
Since they do not cure the disease, there is no need of taking them	Yes	2	1.2
	No	164	98.8
They are good; I do not get many other illnesses when I take them consistently	Yes	103	62
	No	63	38

Table 4.8 below demonstrates that the majority 103(62%) have missed some of prescribed medication in last three months and missing the medicine 101(60.8%) was due to forgetting, 59 (35.5%) stated that dosage schedules was too complex and 57(34.3%) reported bad side effects. This table reveals also some reasons for not missing medications where 61(36.7%) of the adolescents reported that someone remembered us to take medication, 47(28.3%) stated non stigmatization at home.

Table4 8Whether the adolescents have missed medication, reasons for missing and not missing to take drugs (n=166).

Have you missed any prescribed medications	Yes	103	62
	No	63	38
Reasons for missing medication			
Forgot	Yes	101	60.8
	No	65	39.2
Bad side effects	Yes	57	34.3
	No	109	65.7
Did not understand instruction	Yes	37	22.3
	No	129	77.7
Felt better	Yes	19	11.4
	No	147	88.6
The dosage schedule is too complex	Yes	59	35.5
	No	107	64.5
My care giver was not around	Yes	2	1.2
	No	164	98.8
I was at school	Yes	4	2.4
	No	162	97.6
Reasons for not missing to take medications			
Someone remembers me to take medication	Yes	61	36.7

	No	105	63.3
Non stigmatization at home	Yes	47	28.3
	No	119	71.7
I don't have any problem with these medications	Yes	52	31.3
	No	114	68.7
I don't have any side effects on these medications	Yes	55	33.1
	No	111	66.9

Table 4.9 below shows that the majority of adolescents about 102(61.4%) have ever been treated negatively by family members and the manner that the family members treated negatively the adolescents 85(51.2%) was by stigmatization followed by social support withdrawn by family member 67(40.4%) and the least 10(6.0%) was poor financial support.

Table4 9whether the adolescents have been treated negatively and the manner for how they were treated (n=166).

Have you ever been treated negatively by family members	Yes	102	61.4
	No	64	38.6
The manner how the family members treated the adolescents negatively			
Social support was withdrawn by family members	Yes	67	40.4
	No	96	57.8
Discriminated	Yes	16	9.6
	No	150	90.4
Stigmatized	Yes	85	51.2

	No	80	48.5
Isolated by family members	Yes	22	13.3
	No	144	86.7
Poor financial support	Yes	10	6.0
	No	156	94.0

Table 4.10 below shows that there was a significant association between some of the client factors and adherence level where missing of any prescribed drugs has a *p=0.013,* forgetfulness with a *p=0.009,* dosage too complex with a *p=0.044,* someone remembers me to take medication with a *p=0.001,* non stigmatization at home with a *p=0.046,* I don't have any problem with these medications with a *p=0.031,* I don't have any side effects on these medications with a *p=0.064,* isolated by family members with a *p=0.012.*

Table4 10 Association between client factors and level of adherence cross tabulation

Variable	**Test**	**Value**	**df**	**P.value**
They are good, I always feel better whenever I take them*level of adherence	Pearson Chi-Square	8.101	6	0.231
I do not get any change whenever I take them*level of adherence	Pearson Chi-Square	8.780	6	0.186
Have you missed any prescribed medications*level of adherence	Pearson Chi-Square	16.141	6	0.013
Forgot*level of adherence	Pearson Chi-Square	17.031	6	0.009
Bad side effects*level of adherence	Pearson Chi-Square	10.244	6	0.115
Did not understand instruction	Pearson Chi-Square	9.517	6	0.147
Felt better*level of adherence	Pearson Chi-Square	11.235	6	0.081
The dosage schedule is too complex*level of adherence	Pearson Chi-Square	12.755	6	0.044
Someone remembers me to take medication*level of adherence	Pearson Chi-Square	21.859	6	0.001

Non stigmatization at home*level of adherence	Pearson Chi-Square	12.848	6	0.046
I don't have any problem with these medications*level of adherence	Pearson Chi-Square	13.850	6	0.031
I don't have any side effects on these medications*level of adherence	Pearson Chi-Square	11.927	6	0.064
Discriminated*level of adherence	Pearson Chi-Square	5.454	6	0.487
Stigmatized*level of adherence	Pearson Chi-Square	3.518	6	0.742
Isolated by family members*level of adherence	Pearson Chi-Square	16.300	6	0.012
Poor financial support*level of adherence	Pearson Chi-Square	4.944	6	0.551

4.3.2. Health care factors

Table 4.11 below shows that for over a half of adolescents 111(66.9%) reported that absence of the results of the collected specimen affected taking regularly medication, 73(44%) affected by judgmental attitude of the health care providers, 51(30.7%) affected by not given adequate information about follow up.

Table4 11The elements that affected taking regularly medications (n=166 for each)

Variables	**Frequency**		**Percent**
Judgmental attitude of the health care providers	Yes	73	44
	No	93	56
Not given adequate health education about how medications should be taken	Yes	26	15.7
	No	140	84.3
Delay in decision for taking the required specimens	Yes	55	33.1
	No	111	66.9
Absence of the results of the collected specimens	Yes	111	66.9
	No	55	33.1
Not given adequate information about the follow up	Yes	51	30.7
	No	115	69.3

Table 4.12 below shows that there was a significant association between heath care provider and level of adherence where not given health education about medication had a *p=0.021*

Table4 12 Association between health care provider factors and level of adherence cross tabulation.

Variables	Test	Value	df	P.value
Judgmental attitude of the health care providers*level of adherence	Pearson Chi-Square	7.706	6	0.260
Not given adequate health education about how medications should be taken*level of adherence	Pearson Chi-Square	14.904	6	0.021
Delay in decision for taking the required specimens*level of adherence	Pearson Chi-Square	1.622	6	0.951
Absence of the results of the collected specimens*level of adherence	Pearson Chi-Square	2.372	6	0.882
Not given adequate information about the follow up*level of adherence.	Pearson Chi-Square	4.282	6	0.639

4.3.3 Institutional factors

Table 4.13 below shows the major elements that were hindering adolescents from taking medication appropriately; 97(58.4%) of the respondents stated insufficient health care providers in the service, 79(47.6%) reported that ART department was together with some other services in the same building and then 64(38.6%) of the adolescents were hindered by travelling long distance to the health facility.

Table below also reveals that majority of participants 110(66.3%) agreed that drugs were always available in the clinic, 86(51.8%) agreed also that the comprehensive care clinic was easily accessible while 92(55.4%) disagreed that they experienced financial problems to access ARV drugs, and 117(70.5%) disagreed that they turned away several times because of lack of drugs in pharmacy at the health facility.

Table4 13 The elements that hindering from taking medication appropriately (n=166)

Variables	**Frequency**		**Percent**
Travelling long distance to the health facility	Yes	64	38.6
	No	102	61.4
Insufficient health care providers in the service of ART.	Yes	97	58.4
	Not	69	41.4
ART department is together with some other services in the same building	Yes	79	47.6
	No	87	52.4
Accessibility of the ART in the health facilities			
Drugs are always available in the clinic	Strongly disagree	1	0.6
	Disagree	14	8.4
	Agree	110	66.3
	Strong agree	41	24.7
The comprehensive care clinic is easily accessible	Strongly disagree	2	1.2
	Disagree	56	33.7
	Agree	86	51.8
	Strong agree	22	13.3
I always experience financial problems while trying to access ARV drugs at the hospital	Strongly disagree	15	9.0
	Disagree	92	55.4
	Agree	57	34.3
	Strong agree	2	1.2
I have been turned away several times because of lack of drugs in pharmacy at the health facility	Strongly disagree	46	27.7
	Disagree	117	70.5
	Agree	2	1.2
	Strong agree	1	0.6

Table 4.14 below shows that there was no significant association between institutional factors and level of adherence.

Table4 14Association between institutional factors and level of adherence cross tabulation

Variable	**Test**	**Value**	**df**	**P.value**
Travelling long distance to the health facility.	Pearson Chi-Square	3.144	6	0.791
Insufficient health care providers in the service of ART.	Pearson Chi-Square	6.672	6	0.352
ART department is together with some other services in the same building.	Pearson Chi-Square	2.053	6	0.915
Level of adherence and accessibility of the ART in the health facilities				
Drugs are always available in the clinic.	Pearson Chi-Square	25.167	18	0.120
The comprehensive care clinic is easily accessible	Pearson Chi-Square	13.615	18	0.754
I always experience financial problems while trying to access ARV drugs at the hospital	Pearson Chi-Square	19.951	18	0.336
I have been turned away several times because of lack of drugs in pharmacy at the health facility	Pearson Chi-Square	11.290	18	0.88

Table 4.15 below shows how some of the factors influence adherence to ART positively and negatively where those factors influencing adherence negatively show that they are influencing non adherence.

Example forgetfulness, complex dosage and being isolated by family members are influencing adherence negatively which means that they are influencing non adherence while ssomeone remembers me to take medication, non stigmatization at home and I don't have any problem with these medications are influencing good adherence.

Table4 15 Multiple regression analysis of factors associated with adherence level

Variable	**Direction to influence adherence**	**T**	**P.value**	**95% Confidence Interval**	
				Lower limit	**Upper limit**
Have you missed any prescribed medications in the last three months	-0.186	-0.513	0.609	-0.903	0.531
Forgot	-0.613	-1.764	0.080	-1.300	0.073
Dosage is too complex	-0.082	-0.477	0.634	-0.257	0.421
Someone remembers me to take medication	0.698	2.160	0.032	-1.336	-0.060
Non stigmatization at home	0.133	0.516	0.606	-0.376	0.643
I don't have any problem with these medications	0.003	0.010	0.992	-0.625	0.618
Isolated by family members	-0.008	-0.035	0.972	-0.413	0.428
Not given adequate health education about how medications should be taken	_0.477	_2.426	0.016	-0.866	-0.089

CHAPTER FIVE: DISCUSSION

5.1 INTRODUCTION

This chapter will discuss the level of adherence to ART among HIV positive adolescents at Gitwe and Ruhango district hospitals' catchment area and also looked into some factors that influence optimal ART adherence.

This chapter shows how the level of adherence from this study is interrelated to other findings observed from others literatures with similar research problem.

5.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS

This study shows that over a half of participants 89(54%) were females whereas 77(46%) were male, this is similar to the study done by Buyu *et al.*, (2016, p 3) on factors affecting adherence to anti-retroviral therapy at Kampala international University Teaching hospital, Bushenyi District, Uganda which show that 159(62%) were females and 96(43%) were males. It is also similar to the study conducted by Res, Dibaba and Hussein, (2017, p 4) on factors associated with non-adherence to antiretroviral therapy among patients with HIV/AIDS in Arsi Zone, Oromia that has shown that 167(54.6%) were females and 139(45.4%) were males. It is also similar to the study done by Filho *et al.*, (2016, p 2) on Factors associated with lack of antiretroviral adherence among adolescents in Rio de Janeiro, Brazil has shown that 47(46%) were male while 59(54%) were female.

In this study half of the adolescents 86(51.8%) were between 10-14 years old and followed by 67(40.4%) between 15-18 years old and 13(7.8%) were 19 years old and this is comparable to the study done by Smith Fawzi *et al.*, (2016, p 4) on mental health and antiretroviral adherence among youth living with HIV in Rwanda where the majority of the participants 90(47%) were between 10-13 years old and 103(53%) were also between 14-17 years old.

This study revealed that 142(85.5%) of the adolescents were still studying and 24(14.5%) were not studying. These contrast to the findings of study conducted by Fawzi *et al.*, (2016, p 4) which showed that 31% did not attend school, 44% were still studying and 25% had finished studies. This is also different to the study done in Nepal on factors influencing adherence to

antiretroviral treatment which has revealed that 127(38.5%) of the respondents did not attend school and 203(61.5%) were studying (Wasti *et al.*, 2012, p 3)

Among the adolescents who were schooling during this study, only 8(5.7%) of them were in boarding school while 142(94.3%) were not boarding at school.

5.3 ADOLESCENTS' ADHERENCE LEVEL TO ANTIRETROVIRAL THERAPY

Reference to Rwanda's Ministry of Health (2018, pg 11) which reported that clients received ART for at least 3-6 months from initiation of ART should demonstrate viral suppression less than 200 copies/mm3 as an indicator of good adherence and when viral load remains above 200 copies/mm3 is an indicator of poor adherence to ART but adherence level is based on different factors which means not only on viral load. This is similar to the study conducted by Martelli et al., (2019, p 3) which demonstrated that 62.5% of the surveyed adolescents had achieved good adherence basing on the viral load measurement and also clients who took ≥95% of the prescribed drugs had achieved viral suppression. Similarly to the survey conducted by Shrestha, Altice and Copenhaver, (2019) where 40% of the participants reported poor adherence to ART and optimal adherence was significantly associate with viral suppression with a $p=0.038$.

The results from this study revealed that among 166 HIV positive adolescents of Gitwe and Ruhango district hospitals' catchment area participated in this study, the majority 136(81.9%) were having poor adherence to ART, 27(16.3%) were having moderate while minority 3(1.8%) were having high adherence. This adherence level is in contrast to that observed by Mbewu, *et al*., (2015) in their study entitled determinants of poor adherence to antiretroviral treatment in young adults where the adherence level was only 61% and 39% of their respondents represented poor adherence so this implies that in our study, 81.9% of the adolescents with poor adherence status were still unsatisfactory when compared to the adherence benchmark of 95% as determined by WHO (2016), which is required for sustained viral load suppression.

The results from this study are in contrast to findings mentioned in the survey conducted by Buyu *et al.*, (2016, p 20) where poor adherence varies <85%, fair between 85-94% and good adherence >95% to the ART and in this study 58.8% of respondents were having good adherence, 23.5% were having fair adherence and 17.6 had poor adherence.

The almost of participants 163(98.2%) were aware of their HIV status except 3(1.8%) who were not knowing their serological status and this is higher than to the results from the study conducted by Asmare *et al.,* (2014, p 4) as 217(54.6%) of participants were aware about HIV/AIDS. This study differs also to the study done by Mitiku *et al.,* (2013, p 3) which highlighted that 188(78.7%) of participants were aware of their HIV status while 51(21.3%) were not and they found that 208(87%) were having good adherence to ART as they had taken >95% of their prescribed ARV drugs for the last 7 days. The results in this study are also differ to the results observed in the study conducted by Yi *et al.,* (2015) on AIDS-related stigma and mental disorders among clients living with HIV in Cambodia where they found that around 60% of HIV-infected persons are unaware of their sero-status and many of them choose to hide it. This study is also different comparable to the study conducted by Filho *et al.*, (2016) which revealed that 78% of the participants were aware of their HIV status while 22% of them were not yet aware of their HIV status.

In this study, 62% of the participants failed to take prescribed ART in the last three months during data collection according the prescription order. This is similar to the study done in China by Zhiwen *et al.*, (2019, p 10) on factors associated with adherence to antiretroviral therapy among HIV+ patients which revealed that among 705 patients (32.9%) reported that they have ever had missed some doses of drugs and 1388 patients (64.7%) didn't miss any dose. This study is in contrast also to the study conducted by Wasti *et al.*, (2012, p 4) which has shown that 139(80.3%) of the respondents failed to take medication as prescribed. This differs to the study conducted by Fawzi *et al.*, (2017) where around 37% of the participants missed to take ART in the past month.

5.3.1 Medication factors

In this study, over a half of adolescents 94(56.6%) take drugs twice a day and 72(43.4%) once a day and the majority of participants 138(83.1%) took below 5 pills per day and 2(1.2%) had taken drugs between 11-15 pills per day. This is similar to the study done by Nziva, M., (2013, p 55) which demonstrated that 74(87%) of the respondents reported to take below 5 pills per day while 9(11.1%) mentioned taking between 6- 10 pills a day and (99%) of those participants stated taking their ART two times per day with less than 5 pills to receive.

Half of the participants 109(65.7%) were reminded by staff to take drugs, 54(32.5%) sometimes and 3(1.8%) were not reminded by staff while the majority of participants 133(80.1%) have been reminded by parent or guardian to take medication and 32(19.3%) were reminded sometimes.
This survey revealed that there was a significant relationship between adherence level and frequency of taking drugs like twice a day, (*p=0.037).*
These results are similar to the findings got from the survey performed by Mitiku, Abdosh and Teklemariam, (2013) which has shown that 86.5% of the participants were taking <5 pills per day and in the same study, but on the analysis it became contrary where according to same study; no number of pills uptake per day that had a significant influence on adherence rate of the participants. They showed also almost a half of the participants 113 (47.3%) were receiving support from the family while 34(14.2%) were getting support from others Mitiku, Abdosh and Teklemariam, (2013) and studies have shown that support from the family and others support people living with HIV were predictors of ART adherence (Largu, Oprea and Manciuc, 2015).

This study revealed also that there was a significant association between adherence level and the extent guard/ parents help the adolescent to take medication on cross tabulation with Chi-square with *p=0.000* and there was also a significant association between adherence level and extent the clinic staff help these adolescents to take medications with a *p=0.000*. This is similar to the study done by Mosha et al., (2019) revealed that there was a significant association with adherence and family support with a *p=0.001*.

This is contrary to what has revealed in the study done by Kim *et al.*, (2017) which showed that there is no significant association between adherence to ART and extent to the friends and family help to remember to take medication among adolescents with *p=0.16*. This is similar to the study done by Mabunda, *et al*., (2019) which demonstrated that patients who use reminders to take drugs were highly to experience better adherence compared to those who didn't use any reminders and clients that use memory aids were 3 times more likely to adhere to the medication than the ones who were not using any aids. This study is also supported by the study conducted also by Anyaike, *et al*., (2019) has shown that the support from friends and the family were significantly associated with treatment adherence.

This study has shown a big role of clinical staff for reminding the adolescents for taking medication and this is in accordance to the study done by Filho *et al.*, (2016) which demonstrated that patients who were taught by a health care workers to take ART, had better adherence.

5.4 FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY

5.4.1 Client Factors

The majority of adolescents 103(62%) consider ART drugs as good and they do not get many other illnesses when they take them while 128(77.1%) stated that they feel better whenever they take them.

This is similar to the study conducted by Tsega, *et al.,* (2015, pg 3) which revealed that 281(80.1%) of respondents were comfortable taking ART while 42(11.9%) were not comfortable. This study differs to the survey done by Nziva. M., (2013, p 40) where 44(50%) of the respondents reported that ART are good and they do not get many other illnesses when they take them whereas 35(40.74%) stated that they felt better whenever they take them.

This study also showed some reasons for not missing to take medications where majority of adolescents reported some people remembered the adolescents to take medication 61(36.7%) and non stigmatization at home 47(28.3%). This is supported by the survey done by Damulira et al., (2019) showed that strengthening family relationships and promoting social support within families caring for adolescents suffering from HIV can be important in addressing ART challenges among adolescents in sub Saharan Africa.

The majority of the respondents in this study 103(62%) have missed some of the prescribed medications in last three months and only 63(38%) have respected the prescription orders. This was due to some different reasons as mentioned by the participants. Those factors are; 101(60.8%) of them reported that it was due to forgetting, 59(35.5%) stated that dosage schedules was too complex, 57(34.3%) reported bad side effects, 37(22.3%) did not understand instructions, 67(40.4%) social support withdrawn by family member and 10(6.0%) poor financial support. This study is similar to the study conducted in Northwest Ethiopia by Dachew, Tesfahunegn and Birhanu, (2014, p 5) that has shown reasons for missing medications as forgetfulness 44(52.3%) and care giver fear to give drugs 12(14.3%). This differs to the study

done by Tsega, *et al*., (2015, p 3) which has shown that missing doses was because of; forgetfulness 29(43.3%), bad attitude toward to ART 2(3%) and side effects 2(3%) but this study is similar to the results observed from the study done by Mitiku, Abdosh and Teklemariam, (2013, p 5) which stated the reasons for missing drugs as forgetfulness 47.2%, some due to travelling 18.9% and being busy 15.1%.

This survey revealed that there was a significant association between adherence level and missing any prescribed medication with *a p=0.013* on cross tabulation with chi-square.

In this survey, there was also a significant association between level of adherence and forget taking medication (*p=0.009),* too complex dosage with a *p=0.044,* someone remembers me to take medication with a *p=0.001,* non stigmatization at home with a *p=0.046,* I don't have any problem with these medications with a *p=0.031* and being isolated by family members with a *p=0.012.*

Multiple regression in this survey was run to determine how different factors were influencing adherence positively and negatively where forgetfulness (p=0.080, CI=-1.300-0.073), complex dosage (p=0.634, CI= -0.257-0.421) and being isolated by family members (p=0.972, CI= -0.413-0.428) and not given adequate health education about how medications should be taken (p=0.016, CI= -0.866-0.089) were influencing adherence negatively which meant that they were influencing non adherence while someone remembers me to take medication (p=0.032, CI: -1.336- -0.060), non stigmatization at home (p=0.606, CI: -0.376-0.643) and I don't have any problem with these medications (p=0.992, CI: -0.625-0.618) were influencing good adherence.

This study revealed that 102(61.4%) have ever been treated negatively by family members.

Among the adolescents who have been treated differently by family member, this survey discovered that the major reason 85(83.3%) was stigmatization, 67(65.6%) stated social support withdrawn by family member, 16(15.6%) mentioned discrimination and 10(9.8%) poor financial support.

This study showed that there was no significant association between adherence level and discrimination (p=*0.487),* bad side effects *(p=0.115)* and poor financial support, (*p=0.551)* on cross tabulation with chi-square.

The results from this study were contrary to the findings from the survey conducted by Okawa, S. et al, (2018) which was demonstrated that stigma, forgetfulness, ART side effects and lack of assistance were affecting adherence.

This is in contrast to the survey done by Heestermans, T. *et al*., (2016) which has demonstrated that there was a significant association between the following factors and adherence to ART; poor financial support (OR=3.36; 95% CI 2.22-5.93), discrimination (OR=2.88; 95% CI 1.31-3.87), and side effects (OR= 2.20; 95% CI 1.58-3.07).

This is also different to the study done by Kim *et al.*, (2017) where multivariate analysis showed that the variables significantly associated with non adherence were missing clinic appointment with OR= 1.55, 95% CI[1.02-2.34]) while the most reported common barriers to ART adherence were forgetfulness (90%, *p=0 .001*), busy performing other issues (11%, *p=0.001*).

5.4.2 Health care provider factors

This survey revealed that many adolescents 111(66.9%) stated the absence of the results of the collected specimen after taking regularly medication, 73(44%) affected by judgmental attitude of the health care providers, 51(30.7%) affected by not given adequate information about follow up.

This study showed that there was a significance association between level of adherence and not being given health education about medication had a *p=0.021*.

This is contrary to the survey conducted by Nabukeera-Barungi, N., et al (2015) where the participants reported that the facilitators of adherence were counseling, supportive health care workers and provision of adequate information to the prescribed medication.

This study revealed also that judgmental attitude of health care providers was not significantly associated with level of adherence to ART with a *p=0.260*. This study is supported by the study done by Kangendo and Gitonga, A., (2017, p 16) which has shown that non-judgmental attitude of health care providers contribute to better adherence to ART.

5.4.3 Institutional factors

In this study, the participants have reported different institutional factors that affect taking medication appropriately as follow: 96(57.8%) insufficient of health care providers in the service, 77(46.4%) of the respondents said that ART department is together with some other services in the same building and then 64(38.6%) interrupted by travelling long distance to the health facility. These results are similar to the findings shown in the study conducted by Kim *et al.*, (2017) that mentioned the barriers of adherence to ART included 14% of the respondents who stated that they had long distance to travel from home to the clinic.

This survey revealed that a half of participants 110(66.3%) agree that drugs are always available in the clinic, 86(51.8%) agree that the comprehensive care clinic is easily accessible while 92(55.4%) disagree that they experience financial problems to access ARV drugs, and 117(70.5%) disagree that they have been turned away several times because of lack of drugs in pharmacy at the health facility and on cross tabulation with chi-square, this study revealed that there is no significance association between adherence level and accessibility of ART in the health facilities. This is in accordance to the study conducted by Nziva, M., (2013) where 47(55.6%) of the participants agreed that medications were always available in the health facility, 76(88.9%) agreed that the comprehensive care clinic was easily accessible while 2(1.9%) agreed that they had turned away from the clinic due to lack of medication in the pharmacy.

This is similar to the study done by Mabunda, K**.,** et al (2019) which showed that there was no significant association between level of adherence and some of institutional factors where drug availability had a $p=0.07$ and reported that the poor adherence was related to the long distance where the clients had to travel to the health facility.

This is in contrast to the study done by Shubber, Z., et al, (2016) which showed that the respondents reported that adherence was negatively affected by the distance to the clinic with 95% CI 13.0%-21.9% and stock outs with 95% CI 11.7%-20.4%.

5.5 Association between social demographic data and factors influencing adherence to antiretroviral.

The results from this study revealed that there was no significant association between socio-demographic data and level of adherence where gender had a *p=0.404*, age (*p=0.059)*, awareness of HIV *(p=0.946),* being still studying *(p=0.721)* and boarding school (*p=0.493).* This is in contrast to the study conducted by Heestermans, T. *et al*., (2016, p 6) that has shown a significant association between socio-demographic data and adherence to ART where gender was having (OR=1.73; 95% CI 1.34 - 2.23), age (OR=1.61; 95% CI 1.25 - 2.06).

This is also contrary to the findings observed from the study done by Mutwa *et al.*, (2014) which showed that lack of privacy to keep and take medication came out as major barrier for adolescents living in congested households, as well the in boarding schools where privacy is almost limited.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 INTRODUCTION

Poor adherence to ART was found as a significant problem among the participants during this study where some of the respondents report that they took medication according to prescription order while others didn't take drugs as ordered.

6.2 CONCLUSION

In this study among 166 participants, over half of the adolescents (81.9%) were having poor adherence to ART, 16.3% were having moderate while only 1.8% were having high adherence. and it was less than 95% recommended by WHO.

This study revealed that the following factors were positively associated with ART adherence: someone remembered the adolescents to take medication, non stigmatization at home, absence of any problem with medications and the extent to which the clinical staff and guardians/parents reminded the adolescents to take medication.

It showed also some of the factors which were negatively affecting adherence to ART: forgetfulness, complex dosage, being isolated by family members and not being given adequate health education about how medications should be taken.

6.3 RECOMMENDATIONS

Nursing administration:

1. There is need for planners and implementers of ART to set up programs for HIV/AIDS isolation and dosage too complex reduction as the manufacturer has to focus on complexity of dosage by producing at least one pill which contains all requirements for reducing this complexity.

2. To organize massive sensitization on the importance of involving the family members/ guardians in that care and follow up of adolescents suffering from HIV infection and also to consider them like other clients hence reducing isolation in the family.

Nursing practice:

3. Health care providers must improve counseling at initiation of ART and during follow-up at hospital and home visits where counseling has to emphasize on the nature of HIV disease, characteristics of ART, advantages of taking medication as prescribed, the purpose of taking medication, and consequences of poor adherence to ART.

4. There is a need for a behavioral training to health care providers for providing adequate health education about how medications should be taken which may create friendly environment between health care providers and clients and this will improve adherence to ART.

5. Extensive Health education about ART medication taking, effects related to poor adherence for parents / guardians of adolescents living with HIV.
6. Adolescents who are taking ART should be encouraged to take all prescribed medication appropriately and report to the health facility any side effects resulted from those drugs.

Nursing education:

7. To highlight the counseling related to the reduction of factors affecting adherence to ART in the curriculum so that the future nurse students play a role in reducing them.

Further researchers:

8. There is need to conduct a qualitative research to get in-depth analysis of the factors influencing ART adherence in the same study population. This should include a wider range of participants.

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APPENDICES

1. RESEARCH TOOL: QUESTIONNAIRE

Dear Participant,

I am called HABUMUGISHA Emmanuel, a scholar from University of Rwanda, College of Medicine and Health Sciences. I am enthralled in ruling out the factors influencing non adherence to antiretroviral therapy among HIV positive adolescents attending District hospitals. Kindly, I appeal your support by providing the accurate information as asked in this questionnaire. The information you give will be handled confidentially and for academic reason only.

Thank you very much.

Nshuti ugiye gusubiza ibi bibazo,

Nitwa HABUMUGISHA Emmanuel, umunyeshuli wiga muri Kaminuza y'u Rwanda, Koleji y'ubuvuzi n'ubumenyi mu by'ubuzima. Ndimo gukora ubushakashatsi ngamije kumenya impamvu zatuma abangavu n'ingimbi bafite virusi itera Sida badafata imiti igabanya ubukana bwa Sida murwego rwo kuzinda. None rero ndabasaba kumfasha gusubiza ibibazo biri muri iri bazwa. Ndabizeza ko amakuru mutanga aragirwa ibanga kandi azakoreshwa mubijyanye n'amasomo ndetse n'ubushakashatsi honyine ntahandi.

Murakoze cyane.

FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG HIV POSITIVE ADOLESCENTS AT SELECTED DISTRICT HOSPITALS' CATCHMENT AREA IN RWANDA.

Questionnaire no…….. Date: …/…. / 2019

Health facility: …….

INSTRUCTIONS/ *AMABWIRIZA*: This questionnaire is to be carried out in an appropriate environment. The area should be private, safe to ensure confidentiality/ Ubu bushakashatsi bugomba gukorerwa ahantu hizewe, utanga amakuru nawe atuje.

Part 1: Socio-demographic information

Ikiciro I: Irangamimerere y'usubiza

Tick your answer in the appropriate box/ *Shyira akamenyetso v mu kazu gafite igisubizo kiri cyo.*

1. What is your gender/ *Igitsina cyawe ni ikihe?*
   a) Female/ *Gore* ☐
   b) Male/ *Gabo* ☐
2. What is your age in completed years/ Imyaka yawe ni ingahe?
   a) 10-14 years old *(hagati ya 10 na 14)* ☐
   b) 15-18 years old *(hagati ya 15 na 18)* ☐
   c) 19 years old *(imyaka 19)* ☐
3. Are you still studying/ *Uri umunyeshuli*? a) Yes/ *Yego* ☐ b) No/ *Oya* ☐

   If yes, are you in boarding school/ *Niba ari yego, wiga uba mu kigo?*

   i) Yes/ *Yego* ☐ ii) No/ *Oya* ☐

Part II: Non adherence/ adherence level to ART therapy.

Ikiciro II: ukudafata imiti igabanya ubukana bwa Sida n'impamvu zibitera

4. Are you aware of your HIV status? a) Yes/ *Yego* ☐ b) No/ *oya* ☐

5. Do you know your previous viral load/Waba uzi umuvuduko wa virusi uherutse kugira?

a) Yes/ *Yego* ☐ b) No/ *oya* ☐

If yes, how many/ *Niba ari yego, nikangahe:* i) <200/mm^3 ☐ or ii) *cyangwa* >200/mm^3 ☐

Medication factors/ Imiti:

6. How often do you take your drugs in a day/ *Nikangahe ufata imiti kumunsi?*

i. Once per day/ *Rimwe kumunsi*. …… ☐

ii. Twice per day/ *Kabiri kumunsi* …… ☐

iii. Three times per day/ *Gatatu kumunsi* …… ☐

7. How many pills do you take in a day/ *Ufata ibinini bingahe kumunsi* (24hrs)?

a) Below 5 pills per day/ *Munsi y'ibinini 5 kumunsi*…….. ☐

b) Between 6-10 pills per day/ *Hagati y'ibinini 6 na 10*..... ☐

c) Between 11-15 pills per day/ *Hagati y'ibinini 11 na 15*…… ☐

d) Between 16-20 pills per day/ *Hagatari y'ibinini 16 na 20* .. ☐

e) More than 20 pills per day/ *Hejuru y'ibinini 20* ……... ☐

8. To what extent does the clinic staff (nurses, doctors, counselors) help you remember to take your medication? Nikukihe kigereranyo abakozi bo kwamuganga (abaforomo (kazi), abaganga, abajyanama) bakwibutsa gufata imiti?

i. Not at all/ Ntabwo babikora ……. ☐

ii. Sometimes? Babikora rimwe na rimwe …… ☐

iii. A lot/ Babikora kenshi gashoboka …… ☐

9. To what extent do your parent/ guardian/ family members help you remember to take your medication? Nikukihe kigereranyo ababyeyi/ abakurera cyangwa umuntu mubana mumuryango bakwibutsa gufata imiti?

i. Not at all/ Ntabwo babikora ……. ☐

ii. Sometimes? Babikora rimwe na rimwe …… ☐

iii. A lot/ Babikora kenshi gashoboka …… ☐

iv. Family/ guardian not aware of my status/ Umuryango/ undera ntabwo baziko mfite virus itera sida …….. ☐

Part III: Factors influencing non-adherence to ART

Ikiciro III: Impamvu zishobora gutuma imiti igabanya ubukana bwa Sida idafatwa uko bikwiye.

Client factors/Umurwayi:

10. In your own opinion how do you see these drugs (ARVs) that you are taking as compared to other drugs*/ Ugereranyi imiti igabanya ubukana bwa Sida nindi miti ufata, uyibona ute?*

a) They are good, I always feel better whenever I take them/ *Nimyiza, numva meze neza iyo ndimo kuyifata*…… ☐

b) I would rather go for prayers or herbs instead/ *Najya mu masengesha cyangwa nkannya imiti y'ibisambu aho kuyifata*…… ☐

c) I do not get any change whenever I take them/ *Iyo nyifashe ntampinduka ngira*…… ☐

d) Since they do not cure the disease, there is no need of taking them/ *Nk'uko itavura Sida, ntampamvu yo kuyifata*…… ☐

e) They are good; I do not get many other illnesses when I take them consistently/ *Nimyiza, iyo ndimo kuyifata numva meze neza* …….. ☐

11. Have you ever missed any of your prescribe medications for the last three months/ Waba warigeze usiba gufata imiti mu mezi atatu ashije?

(i) Yes/ Yego ☐ (ii) No/ Oya ☐

12. If your answer is yes, what were the reasons for missing medications/ Ni ukubera izihe mpamvu? Put a tick where applicable/ Shyira akamenyesho kumpamvu zabiguteye.

a) Forgot/ Kwibagirwa…….. ☐

b) Bad side effect/ Ingaruka zatewe n'imiti…… ☐

c) Did not understand instruction/ Ntabwo nasobanukiwe n'amabwiriza yo kuyifata . ☐

d) Felt better/ *Numvaga norohewe*…… ☐

e) The dosage schedule is too complex/ *Ingano y'umuti iragoranye*……. ……. ☐

f) My care giver was not around/ *Muganga wanjye ntiyarahari* ……. ☐

g) I was at school/ *Narindi ku ishuli*…… ☐

If your answer is no, what have you made consistent taking these medications? Niba igisubizo cyawe ari oya, ni ibiki byagufashije gufata neza iyi miti?

i. Someone remembers me to take them/ Hari umuntu unyibutsa kuyifata …… ☐

ii. Non stigmatization at home/ ntakato abo murugo bampa ……. ☐

iii. I don't have any problem with these medications/ Ntakibazo ngira kuri iyi miti …. ☐

iv. I don't have any side effects on them/ Ntangaruka mfite kuri iyi miti ……. ☐

13. Have you ever been treated differently by family members/ friends because of your HIV status/ *Waba warigeze ufatwa nabi n'umryango cyangwa inshuti zawe kubera ufite virusi itera Sida?*

i) Yes/ *Yego*….. ☐ ii) No/ *Oya*…… ☐

14. If your answer is yes, how/ *Niba igisubizo cyawe ari yego nigute?*

Social support was withdrawn by family members/ *Abagize umuryango baretse kumfasha*…….. ☐

Discriminated/Kurobanura abantu ufite ibyo ugendeyeho…… ☐

Stigmatized/ *Akato* ……..…… ☐

Isolated by family members/ *Ihezwa*……... ☐

Poor financial support …… ☐

Health care provider factors/ Abantu bakora kwa muganga (abaforomo (kazi), abaganga, abajyanama):

15. Which of the following do you think that have affected you from taking regularly your medication? Muri ibi bikurikira nibiki ukeka ko byaba byarabaye imbogamizi mugufata imiti yawe?

i) Judgemental attitude of the health care providers/ Ntabwo abaganga badufata nk'abandi barwayi ……. ☐

ii) Not given adequate health education about how medications should be taken/ Kudahabwa inyigisha z'ukuntu imiti igomba gufatwa …… ☐

iii) Delay in decision for taking the required specimens/ Gutinda gufatirwa ibizamini ..... ☐

iv) Absence of the results of the collected specimens/ Kubura ibisubizo …… ☐

v) Not given adequate information about the follow up/ Kudahabwa amakuru ahagije kuburyo nkurikiranwa ……..... ☐

Institutional factors/ Ivuriro:

16. Which of the following elements that were hindering you from taking medication appropriately? Muri ibi bikurikira, ni ibihe bikubera imbogamizi mugufata imiti?

a. Travelling long distance to the health facility …… ☐
b. Insufficient health care providers in the service of ART/ Abaganga nibake muri serivise dufatiramo imiti ……. ☐
c. ART department is together with some other services in the same building/ Inzu itangirwamo imiti hatangirwamo n'izindi service/ Inzu dufatiramo imiti hangirwa n'indi serivise …… ☐

Accessibility of the ART in the health facilities: ***Kuboneka kw'imiti igabanya ubukana bwa Sida mu mavuriro.***

17.Please select the most appropriate answer (s) in the columns provided by means of 5 Likert scale where (1)= strongly disagree, (2)= disagree, (3)= neutral, (4)= agree, (5)= strongly agree / *Hitamo igisubizo cyangwa ibisubizo nyakuri (1)ntabwo mbyemera nagato SD, (2)ntabwo mbyemera D, (3) ndifashe N, (4) ndabyemera A, (5)ndabyemera cyane SA.*

Item/ ingingo	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
i) Drugs are always available in the clinic. *Imiti iboneka burigihe mu ivuriro.*	1	2	3	4	5
ii) The comprehensive care clinic is easily accessible. *Biroroshye kugera ku ivuriro.*	1	2	3	4	5
iii) I always experience financial problems while trying to access ARV drugs at the hospital. *Mpura n'imbogamizi z'amikoro mu kugera ku ivuriro.*	1	2	3	4	5
iv) I have been turned away several times because of lack of drugs in pharmacy at the health facility. *Nikenshi nagiye nsubira imuhira nta miti kubera kuyibura muri farumasi y'ivuriro.*	1	2	3	4	5

Thanks a lot for your participation/Tubashimiye uruhare rwanyu mwagaragaje, murakoze cyane.

2. PARENTAL/GUARDIAN INFORMED CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

(For adolescents receiving antiretroviral therapy at Ruhango District hospitals' catchment area)

AMASEZERANO Y'UBWUMVIKANE MU KUGIRA URUHARE MUBUSHAKASHATSI HAGATI Y'UMUBYEY CYANGWA URERA UMWANA W'UMWANGAVU N'INGIMBI N'UKORA UBUSHAKASHATSI.

Title of the study/ Umutwe w'ubushakashatsi: Factors influencing non-adherence to antiretroviral therapy among HIV positive adolescents at selected district hospitals' catchment in Rwanda.

Name of researcher/ *Izina ry'umushakashatsi*: Mr HABUMUGISHA Emmanuel

This consent form should be signed by the parent or guardian of HIV+ adolescent taking ART at Gitwe and Ruhango District hospitals' catchment area before decide to participate in this study aiming at exploring factors influencing adherence to antiretroviral therapy among HIV-positive adolescents at selected district hospitals' catchment in Rwanda.

Aya masezerano yo kugira uruhare mubushakashatsi bwiga kumpamvu zatuma abangavu n'ingimbi badafata neza imiti igabanya ubukana bwa Sida mubitaro by'uturere n'ibigonderabuzima bishamikiye kuri ibyo bitaro, harebwa icyakorwa kugirango imiti ifatwe ukobikwiye, agomba gushyirwaho umukono n'umubyeyi cyangwa urera umwana w'umwangavu cyangwa ingimbi urimo gutata imiti mu mavuriro yo mu Karere ka Ruhango.

It comprises two parts/ *Agizwe n'ibice bibiri*:

- The first part consists of detailed information about the research (for the purpose of getting more information related to this research for your understanding)
- *Igice cya mbere kigizwe a'amakuru agendanye n'ubushakashatsi.*
- Second part is for the parental/ guardian consent form that you will sign if you accept that the adolescent may participate in this study.
- *Igice cya kabiri ni amasezerano yo ushyiraho umukono niwemerako umwana wawe cyangwa urera ko agira uruhare mubushakashatsi.*

PART I:

Introduction/ *Iriburiro*

- Your adolescent is invited to participate in this study assessing the factors influencing non-adherence to antiretroviral therapy among HIV positive adolescent at selected District hospitals' catchment in Rwanda. The outcome of this survey will help both health care providers and policy makers to formulate strategies to improve adherence to antiretroviral drugs among HIV positive adolescents in this mentions above catchment area.
- *[Turagusaba n'umwana wawe kwitabira ubu bushakashatsi bugamije kwiga kumpamvu zatuma abangavu n'ingimbi badafata neza imiti iganya ubukana bwa Sida mubitaro by'uturere n'ibigonderabuzima bishamikiye kuri ibyo bitaro, harebwa icyakorwa kugirango imiti ifatwe ukobikwiye. Ibizava muri ubu bushakashatsi bizafasha abayobozi mu gushyiraho ingamba zatuma imiti igabanya ubukana bwa Sida ifatwa neza n'abangavu n'ingimbi bityo ubuzima bwabo bukarushaho kuba bwiza]*.
- You were selected to participate in the study due to being the parent or guardian of the adolescents that meet the inclusion and exclusion criteria whom are taking antiretroviral drugs for 3 months and who are enrolled in Gitwe and Ruhango District hospitals' catchment area during the period of the study.
- *[Watoranyijwe kugira uruhare muri ubu bushakashatsi kubera ko uri umubyeyi umwana w'ingimbi cyangwa uwangavu cyangwa se umurera wujuje ibisabwa aribyo kuba amaze amezi atatu arimo gufata imiti igabanya ubukana bwa Sida kandi kuba ayifatira mu mavuriro ari mu karere ka Ruhango]*
- We gently request you to read this form and ask any questions that you may have before agreeing to participate in the study.
- *[Turagusaba gusoma iyi nyandiko mbere yo kutwemerera kugira uruhare muri ubu bushakashatsi]*.

Aim of the study [*Intego y'ubushakashatsi*]

The aim of the study is to assess the factors influencing non-adherence to antiretroviral therapy among HIV positive adolescent at selected District hospitals' catchment in Rwanda.

[Intego y'ubushakashatsi ni ukwiga impamvu zatuma abangavu n'ingimbi badafata neza imiti iganya ubukana bwa Sida mubitaro by'uturere n'ibigonderabuzima bishamikiye kuri ibyo bitaro, harebwa icyakorwa kugirango imiti ifatwe ukobikwiye].

Description of the study procedures [Uburyo ubushakashatsi buzakorwamo]

The researcher will introduce himself to parents or guardians of potential adolescents explain about the research and request the adolescents to participate in the study. Then the consent form will be signed by both the researcher and the parent or guardian of the adolescent.

[Umushakashatsi azabanza gutanga umwirondoro we, asobanure ikimugenza kubantu bashobora kugira uruhare muri ubu bushakashatsi, nyuma y'ibyo atange ibisobanuro kubijyanye n'ubu bushakashatsi bityo hagati y'umushakashatsi n'umubyeyi cyangwa urera umwana bagirane amasezerano].

If you agree to be in this study, you will be asked to do the following; you will be also shown the questionnaire to be completed by your adolescent onto which they are requested to answer the questions and thereafter you will return the questionnaire to the researcher.

[Nimutwemwerera kugira uruhare muri ubu bushakashatsi, murerekwa urupapuro ruuriho ibibazo dukeneye ko umwana wawe yuzuza bityo nimurangiza murarudusibiza].

Benefits of being in this study [*inyungu zo kugira uruhare muri ubu bushakashatsi*]

There is on immediately benefits that we expect you to gain from this study however your ideas will be valued so much when shaping the strategies to improve the adherence to antiretroviral therapy among adolescents, the information and results from the study will help the researcher to answer the study objectives and questions hence provide a support in improving the adherence to antiretroviral drugs among those adolescents and the results may help also the health care providers for improving follow up.

[Inyungu zo kugira uruhare muri ubu bushakashatsi nuko ibitekerezo byanyu muzatanga bizifashishwa mugushyiraho ingamba zatuma abakora kwa muganga barushaho kwita no gukurikirana abangavu n'ingimbi barimo gufata imiti igabanya ubukana bwa Sida ndetse nabo bakarushaho gufata iyo miti uko bikwiye kugirango barusheho kugira imibereho myiza].

There is no bonus and financial allowance to participants in this study.

[Ntabihembo cyangwa ubundi bufasha buteganijwe guhabwa abantu bazitabira ubu bushakashatsi].

Risks of being in this study [*Ibyago cyangwa ingaruka kubantu bazitabira ubu bushakashatsi].*

There are no associated risks with participating in this study.

[Nta byago biteganijwe bishobora guterwa no kwitabira ubu bushakashatsi].

Confidentiality *[Ibanga]*

This study is anonymous and the information provided by your adolescent will be kept confidential. The questionnaire completed by your adolescents will not have their names on them.

[Ubu bushakashatsi buzakorerwa mu ibanga, nta myirondoro bwite w'abazitabira ubu bushakashatsi uzakenerwa].

The research records in this study will securely stored and all electronic information will be coded and secured using a password computer, and on a password protected files that includes your name and email address and for adolescents.

[Ibisubizo bizatangwa n'abazagira uruhare muri ubu bushakashatsi, bizabikwa muburyo buboneye, azabikwa muri mudasobwa, afungishwe umubare w'ibanga].

With your consent form, the researcher will keep the completed questionnaires and consent and assent forms in a secure and confidential location for a minimum of 5 years. Your consent and assent forms will not be connected to the questionnaires that the adolescents complete.

[Urupapuro rwo kwemera kwtabira ubushakashatsi ntabwo ruzashyirwa hamwe n'impapuro z'ibisubizo umwana wawe cyangwa urera azatanga].

We will not include any information related to you in any report that we may publish which would make it possible to identify you.

[Nta makuru na macye akwerekeyeho kuburyo yagaragaza uwo uriwe azashyirwa mu gitabo turimo kwandika].

Voluntary participation, Refusal or Withdrawal from the study

[Uburenganzira bwo kwemera, kwanga, cyangwa kwikura mu ubushakashatsi]

Taking part in this study is voluntary. Your adolescents may refuse to answer any questions on the questionnaires. You may decide not be in this study. At any time, you may leave the study without affecting your relationship with the investigator of this study or University of Rwanda.

If your adolescent refuses to answer any questions or withdraw from the study, this will not impact his/ her in any loss or benefits which she/he is otherwise entitled.

[Kwitabira ubu bushakashatsi bituruka ku guhitamo kwawe n'umwana wawe. Umwana wawe ashobora kwanga gusubiza ibibazo azabazwa. Mushobora guhitamo kwitabira cyangwa guhagarika ubwitabire muri ubu bushakashatsi igihe icyo aricyo cyose. Muramutse muhisemo kudasubiza ibibazo bijyanye n'ubushakashatsi cyangwa kutitabira ubu bushakashatsi, tugusezeranije ko nta ngaruka bizagira kumibanire yanyu n'umushakashatsi, cyangwa Kaminuza y'u Rwanda. Icyemezo cyanyu ntikizagira ingaruka ku nyungu zanyu bwite musanzwe mufite mukazi cyangwa ahandi].

Data dissemination

[*Uburyo amakuru azava mubushakashatsi azatangazwa*]

Eventually, this research is carried out to fulfil the requirements of Master's degree in Nursing at University of Rwanda. Therefore, the results from this research will be submitted to UR/CMHS, Nursing department and defended in the panel in the form of thesis. However, this research may be published in an international peer reviewed journals and disseminate via national or international conferences, international scientific journals. The researcher can also present the results of the study to study participants when requested. Confidentiality will be kept to all levels of the study; during presentation of the results, the participants will not be mentioned.

[Ubu bushakashatsi burimo gukorwa mu rwego rwo kurangiza ikiciro cya gatatu cya kaminuza mu ishami ry'ubuforomo. Kubwizompamvu ibizava muri ubu bushakashatsi bizamurikwa kuri kaminuza y'u Rwanda ishami ry'ubuvuzi n'ubumenyi bw'ubuzima mu bwoko bw'igitabo cyandikwa n'abarangiza kaminuza. Bushobora ariko gushyirwa mu binyamakuru mpuzamahanga by'ubushakashatsi, cyangwa bukamurikwa mu nama z'ubushakashatsi ku rwego rw'igihugu cyangwa mpuzamahanga. Nanone umushakashatsi ashobora kubumurikira abagize

uruhare muri ubu bushakashatsi. Amakuru y'ibanga azakomeza kugirwa ibanga aho ubu bushakashatsi bwose buzamurikirwa].

Person to contact and to report concerns *[Umuntu wabaza]*

You and your adolescent have the right to ask questions or raise concern about this research study and to have those questions answered by the researcher before, during or after the research. If you have any questions related to the study, at any time don't hesitate to contact the researcher HABUMUGISHA Emmanuel, face to face or at email: ***emugisha28@gmail.com*** or by telephone at cell phone: **0788577751, 0789702913**. If you like the summary of the results, they will be sent to you.

If you have any questions about your rights as a participants or conduct of this study that may have not been answered by the researcher, you may contact the Chairperson of the UR/CMHS IRB at phone number: **0788 490 522** and of the Deputy Chairperson phone number: **0783 340 040**.

[Mufite uburenganzira bwo kubaza ibibazo mushaka kubijyanye n'ubu bushakashatsi igihe icyo aricyo cyose bitasobanuwe mu makuru muzaba mwahawe, haba mu gihe cy'ubushakashatsi cyangwa nyuma yahoo. Mushobora kwegera umushakashatsi mukavugana imbonankubone cyangwase mukamwandikira kuri imeri ye: ***emugisha28@gmail.com****, cyangwa telephone:* ***0788577751, 0789702913****. Nimuba mukeneye amakuru kubyavuye muri ubu bushakashatsi tuzayabaha]*.

Mugihe mugize ibindi bibazo bigendanye n'uburenganzira bwanyu nk'abagize uruhare muri ubu bushakashatsi, mwahamagara ukuriye inteko ishinzwe ubushakashatsi muri kaminuza y'u Rwanda ishami ry'ubuzima n'ubumenyi mu by'ubuzima kuri telefoni: ***0788490522****, cyangwa umwungirije kuri telefoni:* ***0783340040****]*.

PART II (*UMUTWE WA KABIRI*):

Parental/guardian informed consent form to participate in this study/

Amasezerano yo kugira uruhare muri ubu bushakashatsi.

As my adolescent is invited to participate in the study aiming at assessing the factors influencing non-adherence to antiretroviral therapy among HIV positive adolescents at selected District hospitals' catchment in Rwanda.

[Nk'uko umwana wanjye yatumiwe kugira uruhare mubushakashatsi bwibanda ku kwiga ku mpamvu zatuma abangavu n'ingimbi badafata neza imiti iganya ubukana bwa Sida mubitaro by'uturere n'ibigonderabuzima bishamikiye kuri ibyo bitaro, harebwa icyakorwa kugirango imiti ifatwe ukobikwiye. Buzakorerwa mu mavuriro yo mu karere ka Ruhango].

I understood that after accepting my adolescent to participate in this study, I will allow the researcher to distribute the questionnaire to my adolescent, where she/he will answer questions related to the research objectives. I have been told that to participate in this study will not bring any harm or consequences to me as a parent/ guardian of the adolescent and to the adolescent him/herself. I was told also that there are no immediate personal benefits that I and my adolescent will gain from participation in this study. I understood also that there are no financial allowances that we shall get for participating in this study or any other bonuses/gift. We got the name of research owner, his address as well as that of UR/CMHS IRB so that we can contact them any time for asking questions related to this study.

[Maze kwemerera umwana wanjye kugira uruhare muri ubu bushakashatsi, nzemerera umushakashatsi guha urupapuro ruriho ibibazo umwana wanjye kugirango abisubize. Nabwiwe ko ntazindi nyungu nk'amafaranga, cyangwe se ampano nzahabwcyangwa umwana wanjye azahabwa. Nabonye aho twabariza ibibazo bijyanye n'ubu bushakashatsi ya umushakashatsi cyangwa kaminuza y'u Rwanda].

I have got enough time to ask different questions related to this study and I got clear answers. I accept my adolescent to participate in this study voluntary, I understand that we can withdraw from participating in this study at any time without consequences and it can not affect our

relationships with both the researcher, University of Rwanda and the health facility where my adolescent is receiving care related to antiretroviral drugs.

[Nabonye igihe gihagije cyo kubaza ibibazo, ndetse nanyuzwe n'ibisubizo nahawe, ko kugira uruhare muri ubu bushakashatsi ari uburenganzira bw'umuntu, kubyanga cyangwa se kubyemera, ko igihe cyose umuntu ashakiye yakwikura muri ubu bushakashatsi ntibigire ingaruka mu mubanire yanjye cyangwa inyungu bwite zanjye k'umushakashatsi, kaminuza y'u Rwanda cyangwa se ivuriro umwana wanjye afatiramo imiti igabanya ubukana bwa Sida].

Signature of the parent/guardian of the adolescent (participant):

[*Umukono w'umubyeyi cyangwa urera umwana*]:

……

Date/ Taliki ya: …../……/ ……

Parent/guardian of the study participant has got a copy of this consent form/

Umubyeyi cyangwa urera umwana uzagira uruhare muri ubu bushakashatsi yabonye kopi y'aya masezerano.

3. ASSENT FORM FOR PARTICIPATION IN THE STUDY

Project title: **Assessment of factors influencing non-adherence to antiretroviral therapy among HIV positive adolescents at selected district hospitals' catchment area in Rwanda.**

Investigator's Names: HABUMUGISHA Emmanuel, a student in Masters of Science in Nursing Department at UR/CMHS.

We are doing a research study about **factors influencing non-adherence to antiretroviral therapy among HIV positive adolescents at Gitwe and Ruhango district hospitals' catchment area in Rwanda.** A research study is a way to learn more about people. If you decide that you want to be part of this study, you will be asked to sign, read and take 20min to fill the questionnaire.

There are some things about this study you should know. These are no problems or other negative consequences following you after completing the tool.

Not everyone who takes part in this study will benefit. A benefit means that something good happens to you. We think these benefits might be helping us knowing what is happening to the HIV positive adolescents and plan for them accordingly**.**

When we are finished with this study we will write a report about what was learned. This report will not include your name or that you were in the study.

You do not have to be in this study if you do not want to be. If you decide to stop after we begin, that's okay too. Your parents/guardians know about the study too.

You have the right to ask questions about this research study and be answered by the researcher before, during or after the research. If you have any questions related to the study, at any time don't hesitate to contact the researcher HABUMUGISHA Emmanuel, face to face or at email: ***emugisha28@gmail.com*** or by telephone at cell phone: **0788577751, 0789702913**.

If you have any questions about your rights as a participants or conduct of this study that may have not been answered by the researcher, you may contact the Chairperson of the UR/CMHS IRB at phone number: **0788 490 522** and of the Deputy Chairperson phone number: **0783 340 040**.

If you decide, you want to be in this study, please sign your name.

I, _____, want to be in this research study.

_____ _____

(Sign your name here) (Date)

AMASEZERANO YO KUGIRA URUHARE MU BUSHAKASHATSI HAGATI Y'UMWANA N'UMUSHAKASHATSI.

Umutwe w'ubushakashatsi: Kwiga kumpamvu zatuma abana g'abangavu n'ingimbi badafata neza imiti igabanya ubukana bwa Sida mubitaro by'uturere n'ibigonderabuzima bishamikiye kuri ibyo bitaro, harebwa icyakorwa kugirango imiti ifatwe ukobikwiye.

Izina ry'umushakashatsi: HABUMUGISHA Emmanuel, umunyeshuli mu kiciro cya gatau muri kaminuza y'u Rwanda, mu ishami ry'ubuvuzi n'ubumenyi bw'ubuzima.

Ubu bushakashatsi burimo gukorerwa mu bitaro bya Gitwe na Ruhango ndetse n'ibigonderabuzima bishamikiye kuri ibi bitaro, aho umushakashatsi arimo kwiga kumpamvu zatuma abana g'abangavu n'ingimbi badafata neza imiti igabanya ubukana bwa Sida uko bikwiriye harebwa n'icyakorwa kugirango ifatwe ukobikwiye.

Niwemera kugira uruhare muri ubu bushakashatsi bishobora kugutwara igihe kitarenze iminota 20 mu gusubiza ibibazo bijyendanye n'ubu bushakashatsi. Kwitabira ubu bushakashatsi ni ubushake, igihe cyose ushatse kubuvamo biremewe kubuhagarika kandi turakumenyesha ko umubyeyi wawe cyangwa ukurera azi iby'ubu bushakashatsi.

Turakwizeza ko ntangaruka buzakugiraho. Ntanyungu zidasanzwe muzabona muri ubu bushakashatsi uretse ko bizadufasha kumenya impamvu zatuma imiti igabanya ubukana bwa Sida idafatwa uko bikwiye bityo bigafasha abakora kwa muganga kumenya uko babafasha.

Ubu bushakashatsi niburangira tuzakora raporo y'ibyavuyemo kandi turakumenyesha ko nta myirondoro yawe izagaragaramo kugira ngo hatazagira umenya abana bitabiriye ubushakashatsi.

Ufite uburenganzira bwo kubaza aho utasobanukiiwe kandi urahabwa ibisubizo n'umushakashatsi ariwe HABUMUGISHA Emmanuel, ushobora kumubaza imbonankubone, kuri telefoni igendanwa: **0788577751/ 0789702913** cyangwa kuri imeli: emugisha28@gmail.com.

Ushobora no kubaza umuyoobozi ushinzwe ikigo cy'ubushakashatsi muri Kaminuza y'u Rwanda, ishami ry'ubuvuzi n'ubumenyi bw'ubuzima kuri telefoni: **0788490522**, cyangwa umwungirije kuri telefoni: **0783340040**.

Niba wemeye kugira uruhare muri ubu bushakashatsi, turagusaba kwandika izina ryawe no gushyiraho umukono kuri aya masezerano.

Njyewe: …….. …..Umukono: …….. …Tariki ya: ……/…/…..

4. PERMISSION TO USE THE RESEARCH TOOL

Thesis permission

Personnes

- mary musembi <musembi1971@gmail.com>
- déc 22 à 3h58 PM

À

- emugisha28@yahoo.fr

Corps du message

Hi, Emmanuel first i want to apologize for the delay in responding to your request to use my thesis questionnaire and amend where possible, kindly note that i have got no issues on that. Go a head do the necessary amendments so as long as it suites your thesis. I wish you well as you pursue your studies

Regards.

Mary N. MUSEMBI

5. MAP OF GITWE DISTRIC HOSPITAL

Location of Gitwe District Hospital

6. MAP OF RUHANGO DISTRIC HOSPITAL

Location of Ruhango District Hospital

UNIVERSITY OF RWANDA

COLLEGE OF MEDICINE AND HEALTH SCIENCES

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 14/01/2019
Ref: CMHS/IRB/043/2019

HABUMUGISHA Emmanuel
School of Nursing and Midwifery, CMHS, UR

Dear HABUMUGISHA Emmanuel

RE: ETHICAL CLEARANCE

Reference is made to your application for ethical clearance for the study entitled ***"Factors Influencing the Non-Adherance to Antiretroviral Therapy among Adolescents at a Selected District Hospital."***

Having reviewed your protocol and found it satisfying the ethical requirements, your study is hereby granted ethical clearance. The ethical clearance is valid for one year starting from the date it is issued and shall be renewed on request. You will be required to submit the progress report and any major changes made in the proposal during the implementation stage. In addition, at the end, the IRB shall need to be given the final report of your study.

We wish you success in this important study.

Professor Jean Bosco GAHUTU
Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR

Cc:
- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate studies, UR

REPUBLIC OF RWANDA

Ruhango, on March 04th, 2019
No 203/RPH / 2019

SOUTHERN PROVINCE
RUHANGO DISTRICT
RUHANGO PROVINCIAL HOSPITAL
P.O.BOX 33 RUHANGO
Email:ruhango.hospital@moh.gov.rw

To: Emmanuel HABUMUGISHA
School of Nursing and Midwifery, CMHS, UR

Re: Authorization of Research

Reference is made to you letter of 27th February 2019, received in Ruhango Provincial Hospital on 1ST March 2019, Requesting for permission to conduct data collection in Ruhango Provincial Hospital Catchment area, for your dissertation entitled «Factors influencing non adherence to anti retroviral therapy among HIV positive adolescents at Ruhango and Gitwe District Hospital's Catchment area».

Based on Ethical Clearance » signed on 14/1/2019 with Ref: CMHS/IRB/043/2019 from College of Medicine and Health Sciences, University of Rwanda;

I'm pleased to inform you that Ruhango Provincial Hospital has granted authorization to conduct this data collection in Ruhango Provincial Hospital Catchment Area and you are requested to share results with Ruhango Provincial Hospital.

Sincerely,

Dr. Richard USABYINEZA
Director General of Ruhango Provincial Hospital

REPUBLIC OF RWANDA

RUHANGO DISTRICT

GITWE DISTRICT HOSPITAL

E-mail: ggitwehospital@yahoo.fr
On 05th february, 2019
Ref: N°324/HOPG/2019

RE: Authorization for Research data collection

Dear, Emmanuel HABUMUGISHA

Reference is made to the letter dated 24th January 2019 with the afore said subject and this serves to let you know that you are allowed to conduct data collection at Gitwe District hospital and our health centers, in relation with your research on the topic entitled **FACTORS INFLUENCING NON ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG HIV POSITIVE ADOLESCENTS AT GITWE DISTRICT HOSPITAL'S CATCHMENT AREA.**

You will be facilitated to access all needed information through hospital and health centers from our respective adolescents in our catchment area of your interest and this authorization will remain valid for 12 months.

Furthermore, we would request you to share with the hospital and health center management the results of your research and recommendations to build on for further progress.

We wish you a successful research.

Best regards,

Dr. RUKEMBA Zacharie

Director General of Gitwe Hospital

REPUBLIQUE DU RWANDA
HOPITAL GITWE
B.P.1 NYABISINDU
RWANDA
"A.P.A.G"
ASSOCIATION DES PARENTS ADVENTISTES DE GITWE

Cc:

- **Director of Administrative and Finance**
- **Clinical Director**
- **Direcor of Nurses**
- **Human Resourse**