



**INSTITUTE OF HEALTH**

**FACULTY OF PUBLIC HEALTH**

**DEPARTMENT OF HEALTH, BEHAVIOR, AND SOCIETY**

**LIVED EXPERIENCE OF YOUTH LIVING WITH HIV AND ATTENDING JIMMA HEALTH CENTER AND JIMMA UNIVERSITY MEDICAL CENTER, JIMMA TOWN, OROMIA, ETHIOPIA:**

**A PHENOMENOLOGICAL STUDY**

**BY: ALEMU MITIKU ETANA (BSc)**

**REASERCH THESIS TO BE SUBMITTED TO JIMMA UNIVERSITY, INSTITUTE OF HEALTH, DEPARTMENT OF HEALTH, BEHAVIOR, AND SOCIETY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF PUBLIC HEALTH IN HEALTH PROMOTION AND HEALTH BEHAVIOR**

**JIMMA, ETHIOPIA**

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I have incorporated the suggestion and modification given and got the approval of my advisors. Hence, I hereby kindly request the department to allow me to submit my thesis for final submission.

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We, the thesis advisors has evaluated the contents of the thesis and found it to be acceptable executed according to the approved proposal, written according to the standards and formats of the university and is ready to be submitted. Hence, we recommend the thesis to be submitted for department

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## **Declaration**

I, Alemu Mitiku Etana hereby declare that this **MPH in health promotion and health behavior** thesis is my original work (except where acknowledgments indicate otherwise) and has not been presented for a degree in this or any other university, and all source of material used for this thesis have been duly acknowledged. Moreover, the undersigned agree to accept all responsibilities for the scientific and ethical necessary advice and approval in the course of the research result. I provided timely progress reports to my advisor and find the necessary advice and approval in the course of the research. I was communicated timely with all stakeholders in research process.

This thesis is submitted in partial fulfillment of the requirements for masters of public health (MPH) degree at Jimma University. The thesis is deposited in the Jimma university library and is made available to borrowers under the rules of library. I seriously declare that this thesis has not been submitted to any other institution anywhere for the award of any academic degree, diploma or certificate.

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## **Abstract**

**Introduction:** *In Ethiopia youth are often under served and given insufficient priority in many HIV programs, with poor access to and uptake of HIV counseling and linkage to treatment and care. Much of the research on youth living with HIV in Ethiopia has been confined to the epidemiology of sexually acquired HIV infection amongst 15-24 year olds with considerable emphasis on primary prevention of HIV infection among youths and minimal attention on lived experiences of youth living with HIV.*

**Objectives:** *The main objective of this study is to explore the lived experience of youth living with HIV in Jimma health center and Jimma university medical center.*

**Methods:** *Descriptive phenomenological study design was carried out to explore the lived experience of purposively selected youth living with HIV in Jimma health center and Jimma university medical center. Data was collected through in depth interviews using a semi structured interview guide, and data were analyzed using qualitative data management software Atlas ti.version 7.5.18*

**Results:** *Eleven youths living with HIV participated in the study, and eight of them were females, while the remaining three were males. These youth reported as they had support from youth club, families and ART clinics, while fear of revealing one's own status, and social stigma are some of challenges they have faced, especially majorities don't want to disclose their own status because of fear of stigma and discrimination. Youth had ever skilled psychological experience of Feeling of guilty, anxiety about future life, low self-esteem and boredom of drug dependency. Cope up with problem was common among youth living with HIV where all reported self-concealment, religiosity and escape avoidance as coping strategy.*

**Conclusion and Recommendation:** *Youth participants in this study experience difficulties linked to rejection, stigma and prejudice, lack of meaningful sexual relationship, and lack of sufficient support. Particularly, youths living with HIV encounter barriers to accessing health care services due to HIV-related stigma in the community context, which puts their health at risk and also youths living with HIV exhibited psychological suffering, including boredom of drug dependency, impaired self-esteem and guilty of feeling. This study recommends that ART center health facilities as they implement differentiated service delivery towards ensuring a continuum of HIV care that accurately addresses youth needs in a respectful, effective and efficient manner.*

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## **LIST OF ABBREVIATIONS AND ACRONYMS**

AIDS:	Acquired Immunodeficiency Syndrome
ART:	Antiretroviral Therapy
AS:	Adherence Supporter
CDC:	Communicable Disease Control
CM:	Case Manager
COART:	Currently On Anti-Retroviral Therapy
DSDA	Differentiated Service Delivery Approach
CSW:	Commercial Sex Worker
DHIS:	Data Health Information System
EDHS:	Ethiopian Demographic Health Survey
HIV:	Human Immunodeficiency Virus
JUMC:	Jimma University Medical Center
NCS:	National Case Survey
PSS:	Psychosocial Support
SHGGH:	Shanen Gibe General Hospital
SNS:	Social Network Service/Strategy
SRH:	Sexual Reproductive Health
USA:	United States America
WHO:	World Health Organization
YLWHA:	Youth Living With Human Immunodeficiency Virus

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## CHAPTER ONE

### 1. INTRODUCTION

#### 1.1. Background of the study

Acquired Immunodeficiency Syndrome (AIDS) is caused by a virus called Human Immunodeficiency Virus(HIV), when a person is infected with HIV, the virus infects and can kill certain cells in the immune system and developed to advanced stage of disease(1). The first evidence of HIV epidemic in Ethiopia was detected in 1984. Since then, HIV/ AIDS has claimed the lives of millions and has left behind hundreds of thousands of youth(2). In Ethiopia antiretroviral (ARV) service was launched in January 2003 and public hospitals start providing free ART in March 2005. Recently ART service is being available in more than 1361 health facilities of which around 909 are health centers(3). In Ethiopia adolescents and youth have become high-risk groups in recent years(4). The World Health Organization (WHO) defines adolescents as those between the ages of 10-19 years and those 15-24 years as youth whereas, the national youth policy of Ethiopia classifies youth as those between the ages of 15-29 years, Ethiopia has a rapidly growing population of adolescents and youth 33.8% of the estimated total population(5). HIV is one of the main problems with regard to public health, with greater representation in developing countries. Africa is the most affected region , where almost two thirds of new HIV infections can be found(6). While HIV transmission has been substantially reduced in the past decade. Young people live with HIV globally with 40% of all new infections occurring among youth aged 15–24 years. According to global AIDS monitoring survey 2021, of the estimated 38.0 million people living with HIV worldwide and estimated 2.78 million were adolescents and youth aged 15–24 years. In the same year, 310,000 children and adolescents were newly infected with HIV and 120,000 children and adolescents died of AIDS-related causes(8). Youth is a dynamic time of life, defined by physical, emotional, cognitive and social transitions. Many of these transitions increase Youth' vulnerability to HIV infection while necessitating unique approaches to treatment. Living with HIV as a Youth raises the exigency for effective support and guidance to ensure they traverse through this developmental stage(9).

According to save the children report 2018 each day in over 1,100 children and adolescents (age 0-19) around the world became infected with HIV(10). National HIV prevalence among adult population aged 15-49 years was 0.9% and HIV prevalence in youth age 15-24 was relatively

low for both sexes, but woman age 15-24 have a threefold higher HIV prevalence than men age 15-24(2). There is no cure for HIV, but with proper treatment and care, most people with HIV can avoid getting AIDS, stay healthy and live a long life(11). The ultimate goal of HIV continuum care is to achieve viral suppression, which means the amount of HIV in the body is very low or undetectable, this is important for youth living with HIV to stay healthy, have improved quality of life, and live longer(12). This study is so aimed to explore lived experience of youth living with HIV/AIDS among youth attending ART Clinic in Jimma Health Center and JUMC, Jimma, South West Ethiopia.

## **1.2. Statement of the Problem**

Worldwide, an estimated 38 million people are currently living with HIV, and some 20 million people have already died, with the worst of the epidemic centered on sub-Saharan Africa(8). Globally there are 1.6 billion people aged 15-24—the largest generation of adolescents and young people, women aged 15-24, have HIV infection rates twice as high as in young men, and account for 22% of all new HIV infections and young people aged 15–24 accounted for 40% of new HIV infections (5). Mortality due to it has been decreasing globally but age disaggregated data indicated that death among young population, particularly youth is not yet declining and apparently it has tripled. In Ethiopia, 722,248 people lived with HIV, and there were 22,827 new HIV infections and 14,872 people died from HIV/AIDS in 2017 children, adolescents and young adults have become high-risk groups in recent years(10). HIV is an important health problem worldwide, and the number of people living with HIV worldwide continued to grow in every region of the world, youth are key populations who are particularly vulnerable to HIV infection(13).

There are many reasons for the growing attention to the health of adolescents and youth in Ethiopia. First, this group comprises a significant proportion (33.8%) of the country's population. Second, as this cohort joins the workforce, the foundations laid in health will have profound implications for social, political, and economic development. Third, healthy youth are a key asset and resource, with great potential to contribute to their families, communities and the nation both at present and in the future as actors in social change, not simply beneficiaries of social programs(14). Data are not generally available for youth aged 15-24 years, even though many engage in sex or other higher risk behaviors much earlier. Limited amount of research has been done regarding the assessment of adolescent health and behavior(15). Particularly on HIV,

current surveys are limited to collect data on adolescents aged 15–19 years because of the challenges in getting parental approval for their involvement in surveys and a lack of age-appropriate for adolescent (16)(17).

AIDS is the second leading cause of death among adolescents and youth in Africa, several comprehensive prevention projects are being implemented for adolescent and youth in settings with a high incidence of HIV infections(7). Today globally young people (15-24 ) account for 40 per cent of all new adult HIV infections(18). Globally, each day more than 2400 youth become infected with HIV and some five million young people are living with HIV. Among youth living with HIV 3.6 million (78%) live in sub-Saharan Africa (19). Nevertheless, very little attention has been given to youths living with HIV in the region(20). Progress among youth's quality health care is not sufficient or quick enough, and is not reaching many of the populations most at risk for HIV infection. Human rights violations, along with widespread stigmatization and discrimination, continue to delay access to health services, particularly for youth age 15-24 and key populations (21). According to the national family health survey reports, only 36% of male youths and 20% of females had a 'comprehensive knowledge about HIV/AIDS which includes knowledge about condoms as a preventive measure, knowing that an AIDS-afflicted person can still look healthy, and rejecting to AIDS-related misconceptions(22).

In Ethiopia, youth are often under served and given insufficient priority in many HIV programs, with poor access to and uptake of HIV counseling and linkage to treatment and care(2). Routine program and published research on treatment outcomes among adolescents and youth on ART show worse adherence, retention, poor practice to attend ART clinic and survival in these groups compared with older adults (14).The health problem of this age group are often neglected, youth living with HIV in Ethiopia were twice more likely to be lost to follow up from HIV care compared with adult age and 67.4% death reported during the first year of follow-up(23). Much of the research on youth living with HIV in Ethiopia has been confined to the epidemiology of sexually acquired HIV infection amongst 15-24 year olds with considerable emphasis on primary prevention of HIV infection among youths and minimal attention on lived experiences of youths who are already infected(24). Consequently, a shred of strong evidence is needed on youths lived experience, perception of their treatment processes, their relationship with healthcare professionals, and their experiences in healthcare environments to inform creative and targeted

solutions that will bridge research gaps, inform policy and improve HIV treatment outcomes for youth's(5)(25).

Therefore, this qualitative phenomenological study will address Youths living with HIV perspectives regarding their lived experience while receiving healthcare services and explores how their sense of self is influenced after being labeled as ill, as well as youth coping strategy, their thoughts about ART continuum care, challenges and barriers encountered by youth and their lives in their life cycle. This study will also attempt to fill gaps in research that allows for better understanding of lived experience of youth living with HIV in Ethiopia.

## CHAPTER TWO

### 2. LITERATURE REVIEW

Youth living with HIV are facing and experiencing variety of challenges in their everyday lives, this include stigma, discrimination and lack of social support(26). Stigmatization possesses a problem for both the persons affected by HIV/AIDS as well as their families(27). A study conducted in united state report living with a chronic illness such as HIV can lead to psychological stress that can build over a long time. Youth living with HIV are twice as likely to be diagnosed with major depressive disorder also youth living with HIV may have decreased social functioning in comparison with their peers(28). There is also challenge of disclosure of serostatus. The study conducted in Cameroon reveal that youth living with HIV challenge include disclosure of serostatus, financial problem, long patient waiting time, poor quality of patient reception, reproductive health challenges, stigma, overcrowding and inadequate counseling at the HIV clinics(29). Studies conducted in East Africa highlighted financial stress or poverty as a challenge affecting YLWHA and as one of the causes for non-adherence to treatment(30).

Study conducted in Ethiopia report that youth living with HIV are not included in routine health services, further reducing the already limited access of many adolescent and youth to sexual and reproductive health services. Rapid virtual research has highlighted the challenges that young people living with HIV are facing in rural communities in Afar, Amhara, Oromia, and in Dire Dawa city but as yet very little is known about the specific experiences of vulnerable urban youth in Ethiopia(31). In Ethiopia youth living with HIV develop coping strategies to reduce the psychological suffering of youth living with HIV, youth living with HIV use coping modes of withdrawal, self-control and positive reappraisal were predominantly report, also sometimes youth use responsibility acceptance, escape avoidance and confrontation as coping strategy(12).

#### 2.1.1. Disclosure of their HIV serostatus for others and stigma

A phenomenological study conducted in Ethiopia reports, disclosing HIV serostatus to others is not easy for most youth. Youth believed that, disclosure of their serostatus may predispose them for rejection, stigma and discrimination by people around them. So they don't support to disclose their status to others. They believed the fact that they did not disclose their status for others has benefitted them very much, because they said that they do everything they need freely including

engaging in sexual relations without any threat of people's judgment, stigma and discrimination(20). A lived experience of youth's Studies conducted in Spain reveals some seropositive people take the views of the health professionals who treat them as a reference point because of all the knowledge which they have concerning health. That is why some of these professionals' practices or attitudes can make people with the virus internalize the discriminatory behaviors that some professionals carry out(6).

HIV-related stigma persists in Ethiopia. Also study conducted in Gahanna reveals that, YLWHA shared their experiences with regard to their status disclosure. They expressed fear of being stigmatized if others get to know about their HIV status. Most of the youth living with HIV expressed fear of being ignored, neglected if their friends or others get to know their HIV status(32). This is supported by a review study on HIV disclosure in Sub-Saharan Africa where caregivers revealed that the fear of stigmatization is one of the barriers to HIV status disclosure. In a related study on status disclosure in South Africa, the findings revealed that the level of felt and anticipated stigma is intense and affects all dimensions of living with HIV /AIDS, particularly disclosure and treatment. Disclosure can be difficult as people may be afraid of the consequences: for example, the threat of rejection and violence by partners and family or discrimination in the community and workplace(2). HIV-related stigma persists in Ethiopia while HIV-related stigma is most common in SNNP, while acceptance is highest in the major cities of Harari, Addis Ababa, and Dire Dawa(32). Youth living with HIV, experienced some form of stigma from family members and neighbors who were preview to their predicament. Youth living with HIV experiences are as a result of the Ghanaian societal perception about HIV disease and the fact that they believe it is a form of punishment from god to the afflicted individuals and their families. They see persons afflicted with the disease as persons who had lived a promiscuous life and for that matter will not want to associate with them in any way(33).

### **2.1.2. Financial problem**

Study conducted in Uganda stated financial constraints because youth living with HIV had lost one or both parents who would fend for them. In several cases, they also reported being neglected by their parents and caretakers. They therefore lacked some fees that public schools levy for lunch, uniforms and books or tuition fees for those who had no access to a public school and had to go to a private one. As a result they were always sent away from school. Some few in boarding schools reported that they could not afford to supplement the school food and that they

also lacked clothes. Majority of the participants stated that they lacked transport fares to go to ART clinics for refills and this affected their medication adherence, health and schooling(34). Study conducted on lived experience of youth living with HIV, in Ethiopia report that the economic status of residents in vulnerable places of all study sites were found to positively contribute to vulnerability to HIV infection. It was found that jobless youth with no regular income and those who are engaged in transient job and small-scale petty trade were identified as vulnerable to HIV infection(35).

### **2.1.3. Sexual and reproductive health challenges**

Challenges related to SRH were reported by study done in Zambia given the lack of communication about SRH between YLHIV and clinic staff. The use of mobile technology to deliver SRH information should also be explored to allow ALHIV to access unbiased information, a strategy that has been adopted to provide young people accurate SRH information in some African countries(36). The youths in the age target 15–24 years are characterized by a strong attraction to the opposite sex and a high desire to engage in sex. For YLWHA, reconciling their HIV status with maintaining confidentiality and having an intimate relationship is a quandary. YLWHA revealed some misconceptions about sexual and reproductive health which are detrimental to their own health and that of their sexual partners. Peer pressure to engage in sexual activity was reported by some youths(31) and they had a challenge of overcoming such pressures in the bid to conform to their peers and avoid being suspected of having HIV. Getting into a relationship, however, also seemed a big predicament. They wondered if they would be accepted by their partners because of their status and feared to transmit HIV to others(37). Percentage of young women and men aged 15–24 who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission is too low in Ethiopia(38). Reports of sexual initiation with commercial sex workers (CSW) vary widely, but a large proportion of unmarried male adolescents and college students report having had sex with commercial sex workers or with older women(22).

### **2.1.4. Psychosocial support (PSS)**

Several studies conducted in east Africa context, reported on various forms of psychosocial support available to YLWHA. The Kenyan study identified that newly diagnosed youths relied mostly on emotional support that involves comfort, empathy, or consultation; information support to help them adjust to their diagnosis by giving them advice, factual knowledge or

suggestions; appraisal support which involves giving them constructive feedback, assurance or validation and instrumental support which involves giving youth something tangible like a service, physical object or tangible skill (39),26),20). Sources of psychosocial support for YLWHA identified were family, friends, clinicians, counselors, support groups, religion, and partners. Peer support for YLWHA throughout their lives was prominently reported(30). Study conducted in USA reveals that many HIV positive youth are not consistently linked into or retained in care. Youth who miss clinic appointments are more likely to develop life threatening opportunistic infections. Poor adherence to ART is also associated with increased secondary HIV transmission(40). Adolescence youth is a time of exploration. The stress of having a chronic illness may prevent some YLH from wanting to participate in psychological exploration especially if they are in denial or are having trouble accepting their HIV status. Dealing with a chronic illness shapes and molds individual identities by altering the individual's view of the world(28). Clinical report provides guidance for the youth in addressing the psychosocial support (PSS) needs of adolescents and young adults living with HIV, which can improve linkage to care and adherence to life-saving antiretroviral (ARV) therapy. Recent national case surveillance (NCS) data for youth defined here as adolescents and young adults 15 to 24 years of age revealed that the burden of HIV/AIDS fell most heavily and disproportionately on Sub Sahara African youth(41).

#### **2.1.5. Individual coping strategies**

A study conducted in America reports youth living with aids use of coping methods focused on positive reappraisal and escape avoidance factors, thus focused on emotion. The main coping strategies used were maintaining confidentiality about their seropositive condition, optimism towards treatment, search for social support, rationalization, social comparison, spirituality or religiosity, avoidance and distraction(12).

Many authors have reported about coping strategies utilized to decrease psychological distress related to youth living with HIV infection. These included employing a support network from lovers and closest friends, concealing their HIV status, and comparing their experiences with others for their self-protection from those who rejected them staying healthy, controlling negative thoughts, and maintaining a positive outlook were other reported strategies. Social support can affect the quality of life of youth with HIV I AIDS. The effect of HIV infection on an individual's quality of life was reported. Findings showed that the social support and quality

of life were significantly interrelated to each other and that the support linked to positive health status in those people with HIV infection. In addition, the perceptions of non-supportiveness from their family and friends were associated with poor health outcomes (42).

#### **2.1.6. Practical barriers to attend ART Clinic**

A study conducted in Peru report Individual barriers to treatment adherence included travelling to clinic and initial side-effects of ART. Travelling to clinic outlined the difficulties of travelling long distances from Amazonian communities to reach Iquitos in order to receive monthly treatment, impacting on treatment adherence. Some found it difficult to afford travel costs. Some participants mentioned difficulties taking time off from work to travel long distances to clinic, resulting in people leaving the treatment(43). Insufficient family support leads to late disclosure of HIV status and poor clinic attendance, especially as children need a caregiver to accompany them to the clinic and the pharmacy through adolescence. Improved family-centered counseling may be an important strategy for addressing these barriers(44). The health care providers' role in the provision of care and support for HIV positive individuals is crucial. The result of this study found the satisfaction of clients with the care provided, in addressing their concern, health education and counseling at every HIV care delivery corner help them to control emotion and adhere to ART medication(45). Health service involvement decreases in adolescence at the same time that family involvement in youth's health care also declines. This situation can have serious negative implications for the youth's future health as he or she may make poor health decisions(28). Both the increasing AIDS-related deaths among youth and the limited studies that exist suggest that youth do not have adequate access to ART(46).

## **2.2. Significance of the study**

Too many youths living with HIV still lack access to comprehensive information and options when it comes to their own health. Prejudice and stigma from service providers and health workers can act as barriers to information and education for youth in need of access to services, especially when it comes to seropositive youth. Understanding barriers and developing interventions focusing on seropositive youth have the greatest impact on increasing HIV continuum care and ART adherence.

Therefore, the finding of this study will help to understand perspectives of youth living with HIV regarding their lived experience while receiving healthcare services and other related factors among HIV continuum care.

Thus, this study will fill the existing information gap and help program planning bodies, Jimma town health office, JZHD, ORHB, FMoH and ART service providers to improve youth quality of life to attain intended control of HIV/AIDS. Also, used as baseline information for policy-makers and other researchers.

## **CHAPTER THREE**

### **3. OBJECTIVE OF STUDY**

#### **3.1. General objectives**

To explore lived experience of youth living with human immunodeficiency virus (HIV\AIDS) among youth attending ART Clinic in Jimma Health Center and JUMC, Jimma, Oromia Region, South, West Ethiopia.

#### **3.2. Specific Objectives**

**The specific objectives of this study are to:**

- Explore the lived experiences of youth living with HIV infection in Jimma health center and JUMC.
- Understand the challenges and barriers encountered by youth living with HIV attending ART clinic in Jimma health center and JUMC.
- Find out coping strategy of youth living with HIV/AIDS in Jimma health center and JUMC.

## CHAPTER FOUR

### 4. METHODS

#### 4.1. Study setting

Jimma town is located at a distance of 352 km Southwest of Addis Ababa. The geographic coordinates of the town are approximately  $7^{\circ}40'$  latitude North and  $36^{\circ}50'$  longitudes east. The study will be conducted in Jimma town, the capital city of Jimma zone. According to central statistics agency (CSA) report as projected in 2015 the town has a total population of 177,900 of these 88,262 men and 89,638 women, as well as youth accounts more than 40,539. There is one referral hospital, one general hospital and four health center including Jimma health center which is the ancient health center initiate ART service starting from 2006 in Jimma zone. Also in Jimma town different NGO's provide HIV testing and counseling service including FGAE (family guidance association Ethiopia), FIDO (fayya integrated for development organization) and OSA (Oromia social service association). According to CDC DHIS January 2022 report, Jimma health center has 1124 clients, JUMC 3123, SHGGH 687, Jimma higher two health center 245 and mendera qoci health center 40, totally 5209 clients are taking ART drugs in Jimma town. In Jimma health center and JUMC from all COART client youth age 15-24 accounts 231 & 607 respectively.

This study was conducted from June 7 to July 14 2022 among youth living with human immunodeficiency virus in Jimma town Jimma University Medical Center.

## **4.2. Study Design**

Descriptive phenomenological study design was carried out to explore the lived experience of youths living with HIV at Jimma health center and JUMC.

### **Phenomenology:**

Phenomenology is interested in the world as it is experienced by human beings within particular contexts and at particular times, rather than in abstract statements about the nature of the world in general. It is concerned with the phenomena that appear in our consciousness as we engage with the world around us(47). Descriptive phenomenology is aimed to explore, analyze, and describe particular phenomena directly and freely from unexamined presuppositions(42).

## **4.3. Study Participant**

Youth attending as an outpatient for ART service at selected health facility during the study period were study participants.

## **4.4. Participant recruitment**

Among 5 health facilities gives ART service in a Jimma town, 1 health center and 1 Hospital were selected purposively for this study. The selection was done by considering its long time ART service experience, site triangulation and high client flow; especially of youth. Without considering mode of HIV acquired, eleven participants was selected purposefully based on the following criteria; 1) youths attending as an outpatient for ART service. 2) Youths living with HIV for more than one year. 3) Youths whose appointment date is during the data collection period.

Youth living with HIV in Jimma health center and Jimma university medical center were accessed based on youth interest and consent. The participants were recruited by principal investigator with the assistance of ART health care providers, social network strategy officer, case manager and adherence supporter to maintain privacy and ethical issue. First day the principal investigator, who is also the data collector, was made discussion with the ART health care provider on how to select youth for the study and next day it was done by two phases. Firstly, the ART health care provider was contact youth while they come for collecting their drugs, asks them if they are willing to participate in the study and refers to the data collector only those who gave consent. Secondly, the data collector was give detail information of the study and asks for written consent or assent. For participants those 15-18 years old, parents/guardian

was asked for consent while they come for collecting their drugs with an adolescent then the minor will approve. Finally, researcher was conduct interview until data saturation was achieved.

#### **4.5. Data collection procedure**

In this study, data were collected directly from the youth living with HIV (YLWH) by means of in-depth individual technique with semi-structured interviews guide. The interviews was audio recorded and took place at a private location with a choice of the participants, also field notes were taken to capture verbal and non-verbal expressions. The time of interview was scheduled based on participant's agreement. Accordingly, interviews period was conducted maximum within 75 minute and minimum 34 minutes. The semi-structure interview guide was employed for this study as it permitted a focused exploration of a specific topic which was valuable for interpreting the participants' feelings towards certain interview and around various responses they gave.

The interview guide was translated in local language; Afan Oromo and Amharic. The interview guide was adapted from previous study(20). Prior to the actual data collection, pretest was done at shanen gibe general hospital (SHGGH) on two clients to learn about the process of interview, content, time it takes and necessary amendments was made based on the interview. The interview guide includes socio demographic characteristic, view on the lived experience of youth living with HIV and all in-depth interviews were conducted by principal investigator.

#### **4.6. Trustworthiness**

These studies require trustworthiness to support the research findings as relevant and worth paying attention. To ensure the credibility of the study, member checking was employed to explore the credibility of results. Summary of transcription was returned to study participants to check for accuracy and resonance with their experiences. If participants disapprove summary of transcription, principal investigator revised a transcript. Also researcher suspends or holds his previous experience and knowledge during data collection, transcription and data analysis to describe essence of phenomenon under investigation. To achieve transferability, the code book was developed to provide context to any one that may examine data after analysis. The principal investigator was given a full description of the study setting. A rich and comprehensive account of youth's experiences of living with HIV was also outlined. An audit trail consisting of field notes, audio recordings, analysis notes and coding details was kept for confirmability and also

the researcher were provide thick, rich, textual and structural descriptions that carry the lived experiences of youth living HIV.

To ensure the dependability of the study, an investigator was maintaining an audit trail by giving a rich description of the research. Supervisors audit the process of inquiry audit trail, research activities, data collection technique and analysis process. participants were interviewed with open ended questions using semi structured interview guide, researcher listen repeatedly all of the recorded interviews and read and re read the transcripts to become familiar with participant and understand the experience in its pre reflective sense. Some of the transcripts was coded by peers manually and analyzed also discussed with peer researchers. Finally, the researcher integrates all the resulting ideas into an exhaustive description of the phenomenon by combining all the theme clusters and emergent themes. Due to the sensitive nature of the study researcher was build a trusting relationship by interrelating the participant's, the researcher is familiar to the study setting and field notes was taken during the research process to provide a dense description.

**Experience of researcher:** Phenomenology is unique because it requires documenting researcher's beliefs from the beginning of the study until the data analysis stage. The role of a qualitative researcher is to interpret for understanding rather than to report. Throughout the research procedure, the researcher monitored his/her assumptions and experiences(48).

I am public health officer who is 30 years old. I have eight years of experience performing and assisting with clinical care in government health facilities. I worked in x health facility as an adolescent youth service officer for two years. I was also assigned as HIV social part coordinator. During my career I had performed different activities such as: - Coordinating and managing health work force, providing HIV testing and counseling, providing linkage HIV positive youth to ART clinic, engaging youth in support group.

The topic of HIV became my interest of mine in 2020 when I was assigned as HIV social support coordinator in X health district. One day I was invited to participate on youth peer group. Just as the program was opened I saw an adolescent girl whose was crying and deeply sad. Then I contact her and asked why she was crying. Then she confessed as her father died when she was grade fifth student and living with her mother while faced economic constraint. Also in detail she mentioned her scenario as below.

She said that *"I was living with my mother. My father passed away when I was a grade five student. No matter what, he supported us in all circumstances. Frankly speaking our life is depending on my father because he is the only person whose generate income for us. He is a long distance truck driver but he passed away by HIV disease. Now a day we have no any income, I am a grade 10 student's, my mother has also HIV. She earned money as a nut retailer on the street and she paid house to rent including other necessities. As you are aware today there is a covid-19 pandemic, means a nut market is collapsed as impact of covid-19. No any customer is here due to fear of covid-19 this affects our life indirectly. Even we have no many to pay house rent. The owner enforced us to leave the home why because we can't pay for him. These are extremely difficult times for us. If we can't pay house for rent, we'll have to live on the streets. Consequently, my mother suggests me as I should participate in commercial sex worker for only one day to pay house rent but I refused and she has since ignored me, again she had cried..."*

After we realize the severity of her issue, we attempted to reassure her with ART health care provider. Additionally we provide her advice and counsel that finding a solution was more important than engaging in such like activities. Finally, in order to provide a quick fix, we collect money from ART clinic staffs and we gave her while encouraging paying the fee. Further we discussed with ART staffs what did we do for this families to offer sustainable solutions, we agreed as shelter was very important to resolve these problem. Without disclosing sero status we wrote a letter to mayor's office concerning Keble's house for this families. After a moment mayor's office accepted our letter and response for our request. At the end of the day they got house from mayor's office. This adolescent scenario was painful and it made me passionate and encourages me to deal with youth living with HIV because, if you could relate to them and listened to them, they would communicate freely about their lives.

#### **4.7. Data analysis**

To ensure data analysis the seven steps of Colaizzi's phenomenological data analysis was employed. The voice recordings obtained from the interviews was transcribed, translated, coded, categorized and finally thematized. Audio records were transcribed verbatim by the interviewer and translate to English language prior to analysis. Analysis of data was done simultaneously with data collection. More over necessary links was identified among themes and sub themes. Each transcript was read several times to gain a sense of the whole content. Throughout a research process any thoughts, feelings, and ideas that arose by the principal investigator due to

previous experience was bracketed or putted aside. This help to explore the phenomenon as experienced by participants themselves.

After compiling all translated word documents; coding and categorization was done using qualitative data management software Atlas ti.version 7.5.18 and Colaizzi's (1978) phenomenological analysis step was used consecutively as follows; Initially the researcher personally conducted the interviews. The audiotapes were transcribed verbatim and the researcher was familiarized with the data, the researcher then extract significant phrases and statements from the transcript that together form a whole meaning of the experience. I read and reread the transcript and analyzed each transcript to identify significant statements from the transcript, the researcher then identified meanings relevant to the phenomenon that arise from a careful consideration of the significant statements. After obtaining formulated meanings from significant statements, the researcher arranged them into clusters of themes. These theme clusters then shrunken into emergent themes. In the fifth stage of analysis, the researcher integrates all the resulting ideas into an exhaustive description of the phenomenon by combining all the theme clusters, emergent themes and formulated meanings into a description to create an overall structure. The researcher described the fundamental structure of the phenomenon to make a finding clear and concise description and finally the researcher returned the fundamental structure statement to all participants for the sake of verification.

Following descriptive phenomenological analysis principles the lived experiences of participants and meanings they gave in their words was considered in coding and categorization. The data was analyzed through thematic analysis similar codes or concepts are grouped into the same categories and related categories form themes. At the end themes was explained and quotes are combines into themes to describe an overall essence of the lived experience of youth living with HIV.

#### **4.8. Ethical consideration**

Ethical clearance was obtained from Jimma university institute of health ethical review committee on 31/05/2022 with Ref No\_ IHPG1/896. The purpose of the study was explained to all participants and informed consent was taken. If the participant was not able to give informed consent due to lack of capacity or less than 18 years old, principal investigator require the assent of the adolescent and permission of the parent or guardian. To ensure confidentiality during data collection and processing pseudo name was used. The collected data was used only for the

purpose of agreed with the participant and not shared with others. Also audio recorded and transcripts were being kept safe.

#### **4.9. Dissemination plan**

The finding of this study will be presented to Jimma university department of health behavior and society. Also it will be disseminated to Jimma university medical center, Jimma health center, Jimma town health office, and Jimma zonal health department. The finding also presented in different seminars, meetings and attempts will be made to publish in a reviewed scientific journal accordingly.

## CHAPTER FIVE

### 5. RESULTS

#### 5.1. Socio demographic characteristics of study participants

Eleven youths living with HIV participated in the study, and eight of them were females, while the remaining three were males; this is due to that there are three times as many females than male HIV positive youth in ART clinic. Six were Muslim religion followers, three were protestant religion followers and the rest two participants are orthodox religion followers. All participants aged between 15 and 24 years. While one of them has officially employee, two is degree students, six were students attending their studies at secondary school, one is elementary school student and the other one is advanced diploma holder. Eight participants were infected perinatally and the other three participants infected behaviorally. All 11 respondents had initiated ART, and all of them had been on ART for periods between 6 to 16 years (table 1). A mean age of the study participants was  $19 \pm 2.66SD$  years ranging from 15-24 years.

**Table 1: Participant's characteristics and demographics of youths living with HIV in Jimma, South West Ethiopia 2022**

Partici pants	Gender	Age	Marital Status	Education	Job	Duration of infection	Mode of HIV acquired
P1	Female	15	Single	Elementary	Student	11 years	Vertically
P2	Female	17	Single	High school	Student	13 years	Vertically
P3	Female	21	Single	Degree	Self employed	7 years	Horizontally
P4	Female	21	Single	Degree	Self employed	10 years	Vertically
P5	Female	22	Single	Diploma	Employee	10 years	Vertically
P6	Female	18	Single	High school	Student	16 years	Vertically
P7	Female	16	Single	High school	Student	12 years	Vertically
P8	Female	17	Single	High school	Student	6 years	Vertically
P9	Male	18	Single	High school	Student	15 years	Vertically
P10	Male	20	Single	Diploma	Self employed	9 years	Horizontally
P11	Male	24	Single	High school	Self employed	12 years	Horizontally

## 5.2. Description of participants' Response

The major findings of the study are summarized under four themes, which includes; 1) Psychological experience of youth living with HIV/AIDS which encompasses; Feeling of guilty, Anxiety about future life, impaired self-esteem and Boredom of drug dependency. 2) Youths source of supports which involves; family support, Peer support and, ART clinic care and support. 3) Challenges faced by youths living with HIV, which involves; Fear and consequences of status disclosure, social stigma and discrimination, lack of meaningful sexual relationship, 4) Coping strategy of YLWH has three sub themes which incorporates; Self-concealment, Religiosity and Escape avoidance.

**Table 2: Major and subordinate themes from lived experience of youth living with HIV in Jimma south west Ethiopia 2022**

	Themes	Sub themes	Categories,
1	Psychological experience of living with HIV/AIDS	❖ Feeling of guilty	Aspiration
		❖ Anxiety about future life	
		❖ Impaired self-esteem	
		❖ Boredom of drug dependency	ART effectiveness Intending novel ART ART adverse effect
2	Source of supports	➤ Family support	
		➤ Peer support	
		➤ Clinic care and support	
3	Challenges faced while living with HIV/AIDS	✓ Fear and consequences of status disclosure	
		✓ Social stigma and discrimination	
		✓ Lack of meaningful sexual relationship	
4	Coping strategy of YLWH	• Self-concealment	
		• Religiosity	
		• Escape avoidance	

## **Theme 1: Psychological experience of living with HIV/AIDS**

### **1.1. Feeling of guilty**

The majority of research participants experienced some level of shame and guilt. They claimed that their sense of guilt was a result of the disease's manner of transmission and cultural perceptions about it. They gave in to conventional perceptions that the sickness only affects promiscuous individuals. Most of people concur that some illnesses are God's punishment.

*“I thought young age was a dangerous life time, I had participated in a lot of risky behaviour, meanwhile with a day I made mistake my life become darken, when I remembered that day I felt guilty and overwhelmed but I have nothing to do” (21 years old female)*

*“When we are younger we were all wrapped up in our sort of stuff and the life we are living today is crucial for our future life, I thought that the life I lived earlier made me HIV positive today”(24 years old male)*

Other 22 years old female participant was acquired HIV perinatally as follows.

*“When I was ill, I blamed my mother, but she was not the one who intentionally infected me, also my mother feels a sense of distraction, she thinks that she had been putting me down but, really she is happy if I don't have HIV”*

Participants' experiences have demonstrated that after knowing they were HIV positive, they felt guilty and lament the encounter. Additionally, behaviorally infected participants despise their prior way of living style and occasionally even admit they deserve the illness, believing that they have paid back a ransom.

*“..... I felt deeply sorry; After obtaining the virus I realized that I was paying the ransom because I was very remorseful, I was the one who caused this situation with a series of bad deeds, now I have to be punished”( a 20 years old male)*

### **1.2. Anxiety about future life**

The majority of youths admitted that they are worried about their future, specifically about getting a job, getting married and succeeding in school. As shown below, they spoke in-depth about a variety of issues. Also in many participants' responses, HIV was described as creating a psychological burden relating to anxiety about future life and sustaining good health into the future.

*“I should not stop my medication because if I stop I won't achieve my goal in life such as becoming an artist” (21 years old female)*

*“I wish to join campus but I worry of what may I do if I fail?” (Other 17 years old female)*

*“I thought that was the end of my life, I can’t go to ART clinic again but my father gave me hope“ (21 years old female)*

*“I want to marry, but seeing my condition like this is pity with my future husband” (21 years old female)*

*“The medicines gave me the chance to live again for me, it is also the major reason I am still living today. Despite the fact that taking medication on a regular basis is uninteresting, I still remembered to take my drug on time. Even in future of my life I would have no other option to live if I hadn't taken my medication” (18 years old female)*

Most of participants want to change their life through conducting different activity but youths describe their dread of applying for jobs due to medical certificate.

*“There is a thing called the future, I want to have constant things for my life but I fear that everything will be done by testing. To be honest, I was afraid to apply for jobs if it may request blood sample for medical issue.” (22 years old female)*

### **Aspiration**

Participants had relied on medication and they had future life plan to achieve their desires. Also youths hoping and imaging what their lives will be like in the future.

*“I want to be doctor and serve youth who are living with HIV. I want to focus on the underprivileged youth. You are aware of what will happen when you approach them and speak to them. They want to express their ideas, but nobody will listen them” (other 17 years old female)*

*“In my future life; I want to get to the next advanced level and even I want to be an enhanced person than those who are HIV free youth” (17 years old female)*

### **1.3. Impaired self-esteem**

The findings of this study show that impaired self-esteem of youth living with HIV. The impaired self-esteem of these youth experienced had an effect on their lives and interactions with other. A youth living with HIV who perceives her/his self to be stigmatized due to her association with other stigmatized individuals would have a negative evaluation of her/his self; Thus, resulting in a low perception of own self.

*“...I remember one day my mother ordered me to collect a drug from ART clinic but just when I was arrived ART clinic, there was a person who knew me was sitting on the bench in ART clinic then I directly turn back to the home without collecting my drugs.” (22 years old female)*

*“I found that when youths were gathered in a classroom and seated, I was unable to interact with them because, if I did, I worried that they might begin to appointing me” (16 years old female)*

The occurrence of impaired self-esteem among youth living with HIV/AIDS was more pronounced among schooling and friendship. The participant’s experienced impaired self-esteem and demonstrates vulnerability at different level. Likewise participants reflect their thought among impaired self-confidence as below.

*“At school when students look at me differently, I thought that probably they know about my status” (17 years old female)*

*“...After I knew my status I thought that I missed something, I am not comfort as other youth sometimes I feel like shy and discouraged” (16 years old female)*

*“ When I thought my life I had anger and depressed, I may live for as long as a normal person but I feel that I am like a person in death row waiting to be executed” (18 years old male).*

#### **1.4. Boredom of drug dependency**

Most youth reported that taking ART every day which has boredom and being dependency. Some also reported that forgetting to take the pills is common. The study participants reveal that it was exhausting to take ART every day, which has unpleasant side effects and a heavy pill load.

*“Frankly speaking always medication is too bored; Also when I randomly get together with my friends and recreate do I feel uncomfortable using my drug; otherwise, if I have a plan to carry my drug in my private satchel, I take it quietly”(20 years old male)*

*“I have bad experience among daily drug intake, continuous medication may need self-confidence and good self-care, I decided on my life and unfortunately I stop drug intake. Whereas ART health care provider counsel and provide me to restart medication while I turn back to treatment now” (21 years old female)*

#### **ART effectiveness**

The context of this study implies that respondents were being confident on ARV medication, participants believe that antiretroviral therapy is not only maintains the health, quality of life, and life expectancy of people living with HIV, but also effectively eliminates the risk of HIV

transmission to their HIV negative sexual partners for those who take their HIV medications as directed and maintain an undetectable viral load.

*“I thought a guy that is free from HIV, if he accepts me first; if I get someone who is free it is okay otherwise I prefer to be alone, since my girlfriend who is living with HIV married to HIV free person now a day both her spouse and kids is negative why because she has good adherence to medication” (other 17 years old female)*

*“...as a result of my ART good adherence, every year my viral load test is revealed that it is undetectable that means it is untransmittable to other” (21 years old female)*

The majority of youths were worried about medicine adherence, thus they use mobile phone alarms as adherence aids, which nearly all youths regularly use to remember to take their medications.

*“I take my medications twice daily every morning and evening, and it is also very difficult to remember when to take because a drug I used is too numerous. I always set a reminder alarm on my phone to take my pills on time, and this helps me to remember the time of my medications even when I'm preoccupied” (20 years old male)*

### **Intending novel ART medication**

In general, the majority of youths in this study favor novel antiretroviral therapy; they advise switching from long-lasting pill antiretroviral therapy to long-lasting injection antiretroviral therapy through studies and giving this subject the attention it deserves.

*“I think that if this antiretroviral medication in tablet form is changed to an injection form it is good also I intended to wait for it. Everyone is hoping and waiting for it, especially all ART users' youths are hoping for injection preparation acting for long time, for instance if administered once acting for long duration like immunization did, we are extremely delighted” (22 years old female)*

*“You know there is a vaccine for Covid-19 but still there is no any vaccination for HIV, this is concern me...” (21 years old female)*

### **ART adverse effect**

Study participants stated that typical adverse effect of ARV medication such like nausea, rash, anorexia and hearing loss. Youths revealed as majority of side effect is happen during early initiation of ART and self-limit. Also youths reported that only rare side effect might need treatment and regimen change.

*“The HIV therapy is a challenging, and the adverse effect is really complex. Let me tell you about how the side effects of the medications have rendered my left ear completely deaf” (22 years old female)*

*“For me, my treatment story of first year ART period is so difficult; always after I had taken a medication within an hour I had a vomit and anorexia but it’s resolved over a time” (21years old female)*

*“After I started medication, I developed general body itching but I informed ART health care provider and he changed medication for me then after I relieved from the symptoms” (24 years old male)*

## **Theme 2: Source of supports**

### **2.1. Family support**

Family was cited as the main support by the majority of participants. Nearly all study participants live with their biological families and extended families, as was already mentioned. Even the participant who lives with foster parents feels as though he/she is with father and mother and sees them as their parents. Accordingly, the majority of participants said that their families, including extended families, provided them with care and support, although some of them also said that they did not receive enough support. The following notes reflect both perspectives:

*“Only my mother helps me by working as daily house maid, she also pays for our rent and other necessities. Also, my mother tries to improve our lives, but she is the only one who provides for us financially, therefore I think that I should work as waiters during the day and go to school in the evenings- - - nodding” (female 15 years old)*

Nine out of the eleven participants reported that they did not receive enough support

*“There is no one to help me and I live with my grandmother, she wouldn’t be better off; I worked on it to make our life better; For example, I am a carter day time and again I also piercing a belt during evening time.”(20 years old male)*

*“..... My mother was a very judicious mother to me; she passed away while I was a grade 4 student. Even I wish my mother were still living, especially when I seeing my friends with their mothers. My father now takes care of me and supports me in all circumstances. He gave me guidance and counsel on my health and schooling as well, and he also believed that if I become a banker” (17 years old)*

*“... For me my mother is not only my supporter also she is my peace even if she is not at home I am agitated and I feel annoyed” (Other 17 years old female)*

## **2.2. Peer support**

The main support system mentioned by the majority of participants is the youth club and psychosocial support. In this educational program, young people who contracted HIV meet together every two weeks to learn, play, have fun, exchange interests, and make new friends. The youth club is split into two sections: one is for members under the age of 15 years pediatric psychosocial support, and the other is for members beyond the age of 15 years. Even while everyone refrains from participating for personal and family reasons, those who do remark that it are beneficial to them and that they enjoy it.

*“Before joining the club of youth living with HIV, I was discriminate myself, but now that I'm a member, I realize that, I'm doing better than other young people” (18 years old male)*

*“Being a member of the psychosocial support group made me feel wonderful; I no longer feel alone” (15 years old female)*

A female university student, age 21, discusses the benefits she receives from psychosocial support as below.

*“There was a so called peer counselling; so since we the same group get together we talk everything and share our feelings freely. I got advantage for what am positive, furthermore there is confidence, awareness towards good ARV adherence is a benefit I gained from youth peer group, also now a days Jimma University pays for all of my educational expenses.”*

*“Always am very happy when I join my fellow in psychosocial youth club because we share ideas on how we can continue taking ARV drugs and about our future life” (24 years old male)*

## **2.3. Clinic care and support**

All study participants continued their ART treatment at the different facility where they began, receiving appropriate care. Nearly all said they got excellent support and benefited greatly from the clinical services. Nearly all of them have extensive follow-up experience in hospitals and have a thorough understanding of their surroundings. They maintain tight ties with clinical staff members like physicians, nurses, and social workers.

*“.....This ART clinic provided us with short-term training in hairdressing, barbering, piano, and guitar playing; in the meantime, we are certified, and we are awaiting materials to utilize what we have learned to use.” (22 years old female)*

*“In an ART clinic every three months, I received a backpack, and an exercise book. The good news is that we also received other training that can be useful for our daily lives” (22 years old female)*

A 20 years old male participant describe health worker good manner practice as mentioned below

*“Here in this ART clinic there is good support for youth living with HIV, just they didn’t consider us as adult people living with HIV”*

*“I thought that we HIV positive youth are healthiest now by an effort of all health care workers in this clinic; my character is somewhat different from other youth and I hate an ARV drug but they amend me. I want to make them delighted by reaching a high progressive level” (21 years old female)*

### **Theme 3: Challenges faced while living with HIV/AIDS**

#### **3.1. Fear and consequences of status disclosure**

In this study fear and consequences of status disclosure indicates that the youth who were in some form of a relationship had not disclosed their HIV status to their friends and other relatives. They indicated that they reason for keeping it secret also feared they will lose their friends if they reveal their status to their friends. Unless that friend who is secret holder and trust with every little detail of life, they preferred living alone than disclosing their HIV status to their friends.

*“To tell the truth, I have a girlfriend, she did not know my status, I did not tell her, and I did not attempt to openly talk, however, if I got a lady that has a real feeling for me, gradually I will tell about me because I know how disclosing own status is helpful but no one considers you as a person if once know your status.”(20 years old male)*

*“One day I was on a vacation and my drug time is up while I was attempting to take my drug privately one of my friends saying me what did you do? Then I told him by imitating as am taking a drug for the treatment of abdominal cramps, I prefer to lying him rather than disclose my health status” (21 years old female)*

Most of participants were not willing to apply for job especially if medical certificate is requested. Also they prefer abandonment rather than performing medical examination, they fear anything need blood sample withdrawal as precondition criteria. They thought that a sample taken might be tested for HIV and somebody may know their status illegally. As a consequence most of participant missed opportunity for job.

*“I want traveling to foreign countries; serving in the military and special force, but I am unable to do so without a medical certificate because you will frequently be asked for one by other people and even for a driver's license. As a result, getting a medical certificate causes anxiety. When blood will be drawn at some point, you will feel fear.” (22 years old female)*

Disclosure exposed participant to stigma and discrimination from individual and from the society as whole. To protect themselves youth disclosed their positive HIV status to best buddy and few people.

*“If others know they will not help me, instead they will blame me and distance themselves away, so at all I don't want anyone to know my status”(15 years old female)*

*“I faced many challenges from my experience if any people know about your status he/she just disappoint you directly, now this is a reason why I make these diseases as a secret” (21 years old female)*

*“...I fear disclosing my status unless special case, I remember once a time I informed my colleague about my health status because he is my best friend for me, also I hope that he keeps my HIV status secret but an event that happened is inverse. For a moment he tried to treat me, through step while just he breaks up our friendship, not only that also he told about my health status to other colleagues” ( 24 years old male)*

### **3.2. Social stigma and discrimination**

Social stigma and discrimination in the context of this study implies that discrimination towards young people with HIV infection was widespread and manifested as the phenomenon of being stigmatized and rejected. These youth's lives and interactions with others were impacted by the discrimination they endured. Family, lovers, friends, neighbors, coworkers, and members of the general public were the sources of the rejections.

*“Most of people are ignorant about HIV, also people think we are useless, we are going to die very soon, and some believe that we were cursed to have HIV” (20 years old male)*

*“I think awareness of most people is somewhat lower, actually it is better than formerly but still community is yet doesn't know about HIV in detail, they view HIV as other thing bad and cursed, we youth most of us didn't bring it by ourselves, we inherited from parents; they don't think that. Even they stigmatise me, they would not have their children to play with me” (18 years old female)*

Of the 11 participants who took part in this study, most of them had their status disclosed to others without their permission. They indicated that most of these persons who indulged in these illegal acts were close family relations and friends.

*“... One day our house rent offended my mother and enforced us to leave her house, who then informed all of the neighbors that we were HIV positive. I'll never forget how I felt on that day and you could be nervous were someone stigmatize you and knows your status incidentally” (15 years old girl)*

Other challenges include are, among other things, lagging behind in education, discrimination and isolation at school, and teachers breach confidentiality when they become aware of the student's HIV status.

*One day in school, “I got into a fight with a boy in my class, and when he attacked me, I tried to bite him. Then, the teacher made unnecessary accusations against me and revealed my status illegally to everyone, including the boy's parent.” (18 years old female)*

Other study participants have also reflected on issue of social stigma as follow:

*“I've been with my girlfriend for more than 8 years, and we talk about everything, including our studies, trips to the mosque and other activities because we love each other so much and have grown up together. However, one day unfortunately I have disclosed my serostatus for her then after she totally ignores me. To your surprise the following morning, after I informed her that I have HIV, I called her at the mosque. Her brother then responded and said she wasn't at home, but I suspected and waited for her for a while. Then, when her mother called her at the fence, I realized that her brother had purposefully claimed that she wasn't at home when in fact she was.” (22 years old female)*

### **3.3. Lack of meaningful sexual relation**

There were varying experiences on when youths should make their sexual debut. While some participants preferred to wait until they found a job and were in their late 20 years, others said they were ok at any time as long as they met the meaningful sexual relation. Most participants desire to date and marry someone who is seropositive like them. Nearly all study participants agree that it is important to disclose one's HIV status before beginning a sexual relationship.

*“I am a human being and when you grow and reach some level you will form a family, so at that moment there is a man who has good thoughts and bad thoughts too. If God helps you, you may*

*get one who has good thoughts, so this thing concerns me very much. I mean sometimes I feel as if I may persist alone, without forming a family.” (21 years old female)*

*“My girlfriend didn’t know my HIV status, I planned to disclose it after I understand her attitude towards HIV positive person if she has a bad attitude, I will stop my relationship without telling her that I am HIV positive but if she has a good approach to HIV positive person, I will tell her about my HIV status. Unless I don’t want to be traumatized again after I disclosed myself “(18 years old male).*

Participants’ highlighted potential consequences of the obligation to disclose one’s HIV status to sexual partners.

*“If you are HIV positive no one is interested to be romantic with you; my girlfriends disregard me because she complains about why you held off telling me until I heard about your status from someone else. Furthermore, I apologized but finally our relation is failed” (20 years old male)*

Majority of the study participant claimed to have engaged in sexual activity while having a boyfriend or girlfriend and due to their serostatus; two of individuals (a male or a female) who had been with partners were rejected by their sexual partners’ who were HIV negative.

According to a 22 years old female study participant who experienced rejection, the circumstance was as follows:

*“Searching for sexual relations is really uninteresting. Usually I don’t start, but once I did. As the relationship grows stronger and lasts a long time, you start to worry about its sustainability. Then finally my boyfriend asked me my status, I told him factual information about my status, but his feeling was very immoral at the time, and as a result, his thoughts were disturbed. Eventually, he accepted me, but his family is not happy right now”*

Participants also thought that if a proposal is made by a seronegative person who can accept them as a seropositive person, they will also accept seronegative individual and also some of youth are unwillingness to engage into sexual relationship till to they generate their own income.

*“I want to have HIV free boyfriend because if am good adherence to my medication the virus is undetectable and untransmittable to other, but even if he accept me I am doubtful about issue of sustainability ” (17 years old female)*

*“I don’t want to have boyfriend until I have been employed” (15 years old female)*

A 20-year-old self-employed male youth regretted his involvement in sexual relation and feel self-distrust.

*“Frankly I am ashamed and doubtful to tell about my status since I have a girlfriend; she doesn’t know my status. Finally, I recommend her for the test because we have lived together for more than two years as a couple, but the test result made me traumatized since she is negative and am known positive. Just as soon as the test was over, she ignored me and our relationship is failed. I become depressed when what I expect doesn’t happen”*

## **Theme 4: Coping strategy of YLWH**

### **4.1. Self-concealment**

All participants in this study attempt to conceal their status and maintain their confidentiality but confidentiality of all the participants was not fully protected in healthcare environments. Health worker and close friends did not take the necessary precautions to protect the confidentiality of the personal information of people receiving services from them. Participants’ accounts corroborated this information.

*“I’m secretive, I don’t tell anyone about my status; I was afraid that he/she would be told for someone else” (female 17 years old)*

Also some participants experienced illegal disclose

*“Since my close friends disclose my status, I sternly warned him about my confidentiality at the moment, and because I was feeling very irate, I even tried to smack him, but he apologized and unfortunately he told my status.” (20 years old male)*

Many participants experience vulnerability from defining experiences, such that vulnerability captures on-going, dynamic processes affecting youth quality of life. As been reported by the youths in this study, the time that the youths spends at the health care facility especially around the dispensary often leads to publicity and places an additional burden on youth those who may not have adequate support from those around them.

*“A pharmacist who dispenses ARV drugs once highly preoccupied to give me a drug, so I stood and waited for him for a long time before deciding to leave the hospital without getting my medications. However, a case manager who works with youth informed him, and I was able to get my medications. You should be aware that when you stand and wait for medications, many people will see you” (16 years old female)*

Another set of participants in this study involved actively hiding negative personal information including feelings and actions.

*“I concealed any negative information about myself; I often prevent any acts that exposed me to disclose my status” (22 years old female)*

*“Always when I loathed myself in addition even if I become sick I don’t won’t anybody knowing about me except a doctors whose treat me” ( 18 years old male)*

#### **4.2. Religiosity**

Another important coping strategy that emerged was praying, all participants became more religious after receiving their HIV diagnoses, which they all accepted as destiny and spirituality also provided a coping strategy for most of the participants.

*“I don’t know the reason but most of the time ‘just I go to church when I was angry and feel bad” (17 years old female)*

A 24 years old male participant explain his own experience as follow

*“I sobbed and questioned how I had acquired HIV while I also pleading my GOD to be free”*  
*“I used holy water. I'm not sure if that is God's doing, but the most important thing is to have faith that it will happen. But if we believe and have a pure heart, it will disappear.”(22 female years old)*

Youth living with HIV had experienced praying to God/Allah for the strength to persevere through difficulties and achieve their life goals. However, none of the respondents reported relying solely on prayer; as shown in the examples below quotes, this mechanism was used in conjunction with other coping mechanisms.

*“My faith is in God and also I take my medication” (15years old female)*  
*“...Throughout my life, I will continue praying to Allah to give me the strength” (18 years old male)*

#### **4.3. Scape avoidance**

Most of participants of this study were escaped from the emotional stress and youth experienced exposed to disclose their status to their friends. Some participants adjusted their perceptions toward HIV infection, developed their personal views about the illness, and avoided themselves from the outside influences. The participants described their experiences as follows:

*“One day when my friends donate blood at school, they asked me to donate blood with them. At a meantime I escaped them as my age is not eligible to donate the blood because I know that my blood is not useful for anybody” (16 years old female)*

*“When anything forces me to disclose my status, I simply escape by joking.” (17 years old female)*

When participants actually exposed to disclose they escape by imitating, a grade ten student participants escape her classmate fellow as below.

*“One day when I was heading to the hospital for an appointment, a classmate requested me to go to the hospital with me. I just mimicked them going to the hospital to ask someone who was admitted, I would have escaped them” (17 years old female)*

*“When my grandmother's grandson lived with us for two years so he could attend school, it was difficult for us to use drugs. When our alarm went off and he inquired as to why your phones were always beeping at two o'clock, I chose to lie rather than reveal that I have HIV/AIDS” (22 years old female)*

## CHAPTER SIX

### 6. DISCUSSION

This study sought to learn about the lived experiences of youth living with HIV in this qualitative study. Therefore a descriptive phenomenological approach was applied. As a result of this study, the four themes of psychological experience of youth's living with HIV/AIDS, youth's source of support, Challenges faced while living with HIV and coping strategy of youth's living with HIV/AIDS were discovered based on the experiences of the HIV-infected youths.

The result of this study indicated that thinking about their status usually results in bad feelings and they prefer to ignore it, anxiety about future life and they also leave their fate to God. Youth do not want to disclose their status to others because of fear of stigma and discrimination. Searching for privacy to take the pills, getting a partner who has similar sero-status are some of the concerns and challenges they had. It is revealed that some of participants have engaged in sexual relation; even with a sero-negative partner. The finding of this study was supported by study conducted on lived experience of youth living with HIV in Addis Ababa, that was reported as youths believed the fact that they did not disclose their status for others has benefitted them, because they do everything they need freely including engaging in sexual relations without any threat of people's judgment, stigma and discrimination(20), this implies that how HIV transmission is ongoing among those population group.

The result of this study reveal that boredom of drug dependency and bad feeling of youth about HIV continuum care because living with HIV requires lifelong treatment with ART and is associated with frequent opportunistic infections especially when optimal adherence to ART is not achieved. The ART medication however poses challenges and limitations within the social spheres of youth living with HIV, consequently the majority of youths in this study favor novel antiretroviral therapy; they advise switching from long-lasting pill antiretroviral therapy to long-lasting injection antiretroviral therapy. The results of this study also showed that antiretroviral therapy not only maintains the health, quality of life, and life expectancy of people living with HIV, but also effectively eliminates the risk of HIV transmission to their HIV negative sexual partners for those who take their HIV medications as directed and maintain an undetectable viral load, whereas research in Zimbabwe and Lesotho report that antiretroviral therapy maintains the health, quality of life, and life expectancy of people living with HIV, which might be due to personal behavior towards optimal adherence(61)(62).

The youth voiced several barriers to attend school while at the same time following their strict medical regimens in addition to sporadic illnesses, the study conducted in Uganda on youth's living with HIV/AIDS also reported bad feeling of youths' towards HIV continuum care (63).

Another psychological experience of the participants in dealing with the lived experience of youth living with HIV is guilt feeling. The experience of the participants shows that they regret their past. Finding of this study have also revealed that regret for the past is a common phenomenon among the youths living with HIV. Particularly, behaviorally infected youths often play a direct role in their infection, and lifelong treatment of HIV. The finding of this study is supported by study conducted in Iran where youths feel about HIV continuum care after linked to care and treatment, because they suspect that about retained in care(39).

The current study showed that impaired self-esteem were study participants experienced a negative feeling towards themselves, failing to achieve goals or desires and lost trust. Also an accumulation of disturbances in self-identity, negative body image and role performance was reported. The finding of this study was supported by study conducted in Indonesia(49). But this finding is oppose with the study conducted in Singapore(50). Which shows that youth' living with HIV has psychological experience of high level depression. Possible reason might be due to stage of the disease and biological factors that contribute to depression among people living with HIV.

In this study, youths living with HIV/AIDS shared their experiences with regard to their status disclosure. Most of participants expressed fear and consequences of status disclosure. This finding is supported by a study conducted on HIV disclosure in sub-Saharan Africa where youths revealed that the fear of stigmatization is one of the barriers to HIV status disclosure(51).

According to finding of this study, some respondents had told at least one member of their family about their status. They did this in the belief that these people would be able to maintain their anonymity and refrain from making their status public. This is supported by a study done on 40 HIV patients in Kampala that found that 95% of respondents admitted to telling someone about their status and of those who did, 84% told only family members. Another case in point is a study done on youth living with HIV in South Africa also similar (33). Also the finding of this study showed that youths living with HIV frequently revealed their status to one trusted family member who is capable of keeping the information about the diagnosis a secret for a long time before disclosing it to others.

All participants of this study have reported a benefit from knowing their HIV status and strongly believed that youth should learn prevention plan of HIV. This finding is similar with studies from India, South Africa, and Uganda where similar population groups have depicted the same self-disclosure benefit from it(52). The finding of this study revealed that the level of felt and anticipated stigma was intense and affects all dimensions of youth living with HIV /AIDS, particularly disclosure and lack of meaningful sexual relation. This finding was supported by study conducted on status disclosure in South Africa, where fear and difficulty of romantic relationship was reported (53). Additionally, this study shows that youth living with HIV/AIDS lack of meaningful sexual relation and youth searching sexual relation has been documented and this is gaining attention as a barrier to ART adherence. Among Youth living with HIV/AIDS enrolled in HIV care and treatment is potentially a first step, this should only be implemented if comprehensive services are available on-site or if referrals can be made to existing programs, This study also in lined with study conducted in other part of Ethiopia, Gahanna and Saudi Arabia (20)(14)(54).

Most participants mentioned that families and caregivers were the main source of support for youth living with HIV/AIDS. Family care is a significant source of support for young people living with HIV and AIDS. Studies from Botswana and India also reported same findings that family care is an important source of support for youth living with HIV /AIDS(55)(56). The health care services and the service providers' approach were other major sources of supports reported by almost all study participants. This finding is consistent with studies reported from Kenya, Rwanda and Somali (57)(58)(59). Also finding of this study report that youth club is an important club of youth living with HIV /AIDS, where they get together every two weeks and learn, share ideas, play together and is an opportunity for mixing with youth of similar status and a way of satisfaction and sharing their experience. This implies that if the health care services are accessible enough and accompanied with improved friendly services, they will produce tangible health outcome among such population group which helped them to adhere with the ART care and treatment.

The findings of this study suggest that Youth living with HIV/AIDS are also in need of comprehensive services, which include not only clinical treatment but also psychological support. This support is especially important since some studies have documented the relationship between experiencing sexual relation and risky sexual behavior among Youth living

with HIV/AIDS (33). Youth living with HIV/AIDS had the experience of feeling at loss which gave rise to the feeling of guilt and shame that they living with HIV. This experience, in turn, resulted in coping strategy in the form of self-concealment, religiosity and escape avoidance about their health condition. Feeling ashamed facilitated the internalization of negative realization, and culminated in more profound forms of self-discrimination(54).

This study found that the fear of stigmatization in youths did not vanish, even after they began treatment. However, some of them persisted from visiting peer groups and Psychosocial Support, which are available at facility level, this is different from study conducted in Saudi Arabia as a result of youth refrained from psychosocial group(54). Therefore, they prefer to receive care from facility far from their residence area and alternative therapies. Previous studies indicate that a minority of participants stated that people behave negatively towards them avoid being close to them or are ostracized from social events, because of their HIV status (60). This implies that HIV related stigma is still the main concern for youths living with HIV. Endeavors to decrease stigma are necessary to focus prompt HIV chronic care and community awareness creation. Most of participants are highly interested if health care workers and other service providers in direct contact with clients need to be familiar with the differentiated services delivery models and to maintain confidentiality of the client, youth favor fast track ART drug refill.

Despite medical advances and their facilitation of longevity, living with HIV remains challenging and being young appears to aggravate this. The multifaceted challenges identified in this study were also found in earlier literature. In the review covering HIV/AIDS knowledge in sub-Saharan Africa, youth were found to experience challenges relating to their psychological health, peer support, and schooling as those found in this study, this study supported by results from Namibia, South Africa, and Malawi shows insufficient support and sake of support especially for youths living with HIV/AIDS(6). However, studies conducted in Saudi Arabia and Egypt reported that unwillingness of youth engagement in youth psychosocial support group (54)(61). This might be due to lack of confidence to participate in a group.

According to the current study, youths used escape-avoidance in order to create new meanings for the stress, facing it with a positive attitude, leading to personal progress. Thus, they attribute new meanings to the HIV in order to see it from a different perspective, that is, a positive perspective. Other study revealed that there are denial and lack of interest in dealing with HIV-related stressors, which may negatively contribute for improving the clinical picture, as it may

seem like a way of fantasizing possible solutions for the problems, without actually taking concrete actions to modify the reality (51).

Spiritual intervention was another coping strategy used by youths living with HIV to cope with their condition. The findings of this study showed that youths living with HIV relied on God to help them to endure their situation. Participants in the study turned to religion as a coping mechanism to accept their health in any way or to find significance. They had to come to terms with the fact that their situation was predetermined. The employment of spiritual practices including daily prayer, Bible and Qur'an reading, and pilgrimage can help people reestablish their connection to the Holy Spirit. After receiving an HIV/AIDS diagnosis, youth reflect on their spirituality and include religious practices in their coping mechanisms, according to research conducted in various cultural contexts. The results of this study are consistent with a qualitative phenomenological study carried out in Saudi Arabia(54). Also in this study self-concealment is another coping strategy of youth's living with HIV/AIDS, whereas Studies conducted in Kenya reported that responsibility acceptance as coping mechanisms of people living with HIV/AIDS that is might be due to population group and fear of failure(62).

Many studies reported on challenges related to disclosure of HIV status. The fear of gossiping, ridiculing, teasing, and losing of friendship caused youth's living with HIV/AIDS to conceal their status and negative personal information from some family members, teachers, and peers which again led to isolation and depression(30). In this study they were found to use several ways to conceal their HIV status, like covert medication use, shunning other identified HIV-positive peers, maintaining confidentiality. Also youths not sharing their family history disclosure to others would lead to rejection or acceptance or extreme anger, and due to this unpredictability, most of youth's living with HIV/AIDS feared to get involved in romantic relationship.

## CHAPTR SEVEN

### 7. CONCLUSION AND RECOMMENDATION

#### 7.1. Conclusion

Youth participants in this study experience difficulties linked to rejection, stigma and prejudice, lack of meaningful sexual relationship, and insufficient support. Youth, on the other hand, participate in sexual debut and unprotected intercourse with both seronegative and seropositive people, and they do not want to report their status due to stigma and discrimination. Regarding the prevention of HIV transmission, this is a highly bothering problem. Most participants wish to have meaningful sexual relation and love mate of negative serostatus but also fear they may remain alone. Consequently, if those young people are not thoroughly examined, alienated, and convinced there is a possible risk for ongoing HIV transmission.

Particularly, youth living with HIV/AIDS encounter barriers to accessing healthcare services due to HIV-related stigma, impaired self-esteem and prejudice in the community context, which puts their health at risk. Additionally youths living with HIV favor fast track ART drug refill. This study identified higher means for emotion centered coping methods used by youths living with aids, that is, methods related to the escape avoidance, religiosity and self-concealment as problem focused coping strategies. The family affective context and religiosity can influence the confrontation of the disease in a positive way.

Also in this study, the effects of HIV disclosure and stigma on youth living with HIV were observed. Youths struggled to openly disclose their HIV status to others due to their fear of stigma and discrimination by others. As they tried to cope with the challenges, youths experienced rejection from peers and community including school. The current study also revealed that youths living with HIV exhibited psychological suffering, including anxiety about future life, boredom of drug dependency and feeling of guilty.

## **7.2. Limitation of the study**

Phenomenology is more likely to include personal bias; researchers may not entirely prevent while describing or analyzing the experience. Despite these limitations, the findings of the research provide an important basis for relevant interventions for the study area.

## **7.3. Recommendation**

Hence based on the findings of this study the following recommendations were forwarded.

### **For ART center health facilities**

- ❖ This study recommends ART center health facilities as they implement DSD towards ensuring a continuum of HIV care that accurately addresses youth needs in a respectful, effective and efficient manner. Implementation of more intensive DSD approach will minimize challenges faced by youth living with HIV and strengthen youths' quality of care; because it include ART refill, clinical consultation and psychosocial support.
- ❖ Also ART facility able to provide better information and more efficient education to be sure that youth get the prevention benefit from ART and health care provider can reduce fear, stigma and discrimination that surround YLWHIV. In addition to their treatment, health professional who works with YLHIV should focus on detecting youth's challenging issue and offering supportive care.

### **For JZHD and Jimma town health office**

- ❖ Jimma zonal health departement and Jimma town health office should create specific sufficient support network at various ART health facilities so that youths living with HIV can walk in and obtain these services. In order to enhance youth quality of life, Jimma zonal health department should expand Psycho social support and youth club peer counseling in all ART center health facilities.

### **FOR Ministry of Health and ORHB**

- ❖ Comprehensive public education on HIV/AIDS, its method of transmission, treatment, and prevention should be provided by health educators. This will enhance peoples' understanding and attitudes toward youths living with HIV. Also confidentiality and privacy policies should be implemented to improve HIV retained care and treatment.

## References:

1. Virus HI. AIDS and HIV Fact Sheet. cpha, HIV Defin. 1985;5(HIV brief concept):25.
2. Mamo SK. National Comprehensive HIV Prevention , Care and Treatment Training for Health care Providers Participant Manual. ART Guidel. 2017;256–7.
3. FMOH. National concolidated guidlines for comprehensive HIV prevention , care and treatment 2018. Kebede, Work. 2018;(WHO):238.
4. Kloos H. HIV / AIDS in Ethiopia : The Epidemic and Social , Economic , and Demographic Impacts. 2001;
5. Health G, Strategy S, Aids TE. Global health sectors strategy on Hiv 2016–2021. switzerland: Geneva HIV departement; 2021. 1–57 p.
6. Arias-colmenero T, M<sup>a</sup> AP, Jes A. Experiences and Attitudes of People with HIV / AIDS : A Systematic Review of Qualitative Studies. Int J Virol AIDS. 2020;1–14.
7. Sheet F, Day WA, Hiv N, Hiv N. Global HIV statistics. 2021;(June):1–6.
8. Women P. 2021 HIV and AIDS Global Snapshot. UNICEF [Internet]. 2021;1–9. Available from: unice united nations, new york USA
9. Amare H, Azage M, Negash M, Getachew A, Desale A, Abebe N. Risky Sexual Behavior and Associated Factors Among Adolescent Students in Tana Haik High School , Bahir Dar , Northern Ethiopia. 2017;3(4):41–7.
10. Sheet F. GLOBAL HEALTH HIV , AIDS AND TB Save the Children envision a world where children and families can live free of. 2018;(October 2004).
11. NAIDS. 2016 Global AIDS Response Progress Report – CANADA – Government of Canada. 2016;(January 2014):1–23.
12. Silva RTS, da Silva RAR, Rodrigues IDC, de Souza Neto VL, da Silva BCO, Souza FM de LC. Estratégias de enfrentamento utilizadas por pessoas vivendo com aids frente à situação da doença. Rev Lat Am Enfermagem. 2018;26.
13. Geneva W. UNAIDS global and regional data 2021 special analysis. Glob Fact Anal. 2021;three(HIV data analysis):1–442.
14. Republic D. NATIONAL ADOLESCENT AND YOUTH. 2020;
15. Qidwai W, Ishaque S, Shah S, Rahim M. Adolescent Lifestyle and Behaviour : A Survey from a Developing Country Adolescent Lifestyle and Behaviour : A Survey from a Developing Country. 2010;(September).

16. Idele P, Gillespie A, Porth T, Suzuki C, Mahy M, Kasedde S, et al. Epidemiology of HIV and AIDS Among Adolescents. *JAIDS J Acquir Immune Defic Syndr.* 2014;66(Supplement 2):S144–53.
17. For C, Control D. Adolescent Behaviors and Experiences Survey — United States , January – June 2021. 2022;71(3).
18. Sheet F. Adolescents, young people and HIV fact sheet data. *It united nations Progr HIV/ADS.* 2020;Two(yoth burden):1–2.
19. Parrish ME, Parrish ME. *A Phenomenological Study of People Living with HIV in Montana.* 2018;
20. Art H, Ababa A, Id NS, Molla M, Ketema B. “ I want to perform and succeed more than those who are HIV-seronegative ” Lived experiences of youth who acquired HIV perinetally and attend Zewditu Memorial. 2021;1–15. Available from: <http://dx.doi.org/10.1371/journal.pone.0251848>
21. 2019 U special analysis. *DATA hiv. geneve swizerland/join UNAIDS.* 2019;3:1–147.
22. Nath A. HIV / AIDS and Indian youth - a review of the literature ( 1980-2008 ) *HIV / AIDS and Indian youth – a review of the literature ( 1980 - 2008 ).* 2015;(April 2009).
23. Id DJ, Abebe W, Taye K, Ruff A, Hallstrom I. Adolescents living with HIV are at higher risk of death and loss to follow up from care : Analysis of cohort data from eight health facilities in Ethiopia. 2019;1–15.
24. pretty patience jena. Exploring the lived experiences of adolescents living with vertically acquired HIV. In: *journalof hiv/AIDS. pretoria;* 2014. p. 1-139 pages.
25. Basha EA, Derseh BT, Wubetu AD, Engidaw NA, Gizachew KD. Factors Affecting Social Support Status of People Living with HIV/AIDS at Selected Hospitals of North Shewa Zone, Amhara Region, Ethiopia. *J Trop Med.* 2021;2021.
26. Sukholuhle Tshuma. The challenges faced by Adolscent. *Univ pretoria.* 2015;120(November):1–120.
27. Seloilwe E, Jack A, Letshabo K, Mokoto M, Kobue M, Muzila R. The African e-Journals Project has digitized full text of articles of eleven social science and humanities journals . This item is from the digital archive maintained by Michigan State University Library . Find more at : HIVI AIDS at the University of Bot. *JAIDS J Acquir Immune Defic Syndr.* 2019;(African journal project).

28. Spiegel L, Mayers A. Psychosocial aspects of AIDS in children and adolescents. *Pediatr Clin North Am.* 1991;38(1):153–67.
29. Ajeh R, Ekane H, Thomas EO, Dzudie A, Jules AN. Perceived Patients ' Satisfaction , Barriers and Implications on Engagement in Antiretroviral Treatment Services in Cameroon within the HIV Test and Treat Context. 2019;(May).
30. Kimera E, Vindevogel S, De Maeyer J, Reynaert D, Engelen AM, Nuwaha F, et al. Challenges and support for quality of life of youths living with HIV/AIDS in schools and larger community in East Africa: A systematic review. *Syst Rev.* 2019;8(1):1–18.
31. Amdeselassie AT, Emirie G, Iyasu A, Gezahegne K, Jones N, Mitiku E. Experiences of vulnerable urban youth under covid-19 : the case of street- connected youth and young people involved in commercial sex work. 2020;(August).
32. Survey, Health E. HIV / AIDS in Ethiopia. 2016;1-24 pages.
33. Abdulrezaq doat E. Lived Experiences of Adolescent Living with human immunodeficiency virus in Ghana\_ A Phenomenology Study. 2021. p. 1–17.
34. Marni, Nurtanti S, Handayani S, Ratnasari NY, Susanto T. The Lived Experience of Women with HIV/AIDS: A Qualitative Study. *Int J Caring Sci.* 2018;11(3).
35. Kaba M, Taye G, Gizaw M, Mitiku I, Adugna Z, Tesfaye A. Original article A qualitative study of vulnerability to HIV infection : Places and persons in urban settings of Ethiopia. 2016;
36. Mccarraher DR, Packer C, Mercer S, Dennis A, Banda H, Nyambe N, et al. Adolescents living with HIV in the Copperbelt Province of Zambia : Their reproductive health needs and experiences. 2018;1–13.
37. Senyurek G, Kavas MV, Ulman YI. Lived experiences of people living with HIV : a descriptive qualitative analysis of their perceptions of themselves , their social spheres , healthcare professionals and the challenges they face daily. 2021;1–15. Available from: <http://g.senyurek@amsterdamc.nl>
38. Indicators C. GLOBAL AIDS RESPONSE PROGRESS REPORTING 2014 Construction of Core Indicators for monitoring the 2011 United Nations Political Declaration on HIV and AIDS. 2014;
39. Imani B, Zandi S, Mirzaei M. The lived experience of HIV - infected patients in the face of a positive diagnosis of the disease : a phenomenological study. *AIDS Res Ther*

- [Internet]. 2021;1–8. Available from: <https://doi.org/10.1186/s12981-021-00421-4>
40. Martinez J, Chakraborty R, Aldrovandi GM, Chadwick EG, Cooper ER, Kourtis A, et al. Psychosocial support for youth living with HIV. *Pediatrics*. 2014;133(3):558–62.
  41. american academy. Psychosocial Support for Youth Living With HIV \_ Pediatrics \_ American Academy of Pediatrics. In Washington: American Academy of Hospice and Palliative Medicine; 2014. p. 1–18.
  42. Suwisith N. Edith Cowan University. Grants Regist 2022. 2021;376–7.
  43. Tattsbridge J, Wiskin C, Wildt G De, Llavall AC, Ramal-asayag C. HIV understanding , experiences and perceptions of HIV-positive men who have sex with men in Amazonian Peru : a qualitative study. 2020;1–17.
  44. Provinces N. YOUTH LIVING WITH HIV IN MOZAMBIQUE — REACHING THE LAST 95. 2019.
  45. Letta S, Tefera M, Asegid A, Girma E. Serodiscordant as Means of Support : Lived Experiences of HIV Positive Journal of Womens Health Care Serodiscordant as Means of Support : Lived Experiences of HIV Positive Mothers In Harar , Eastern Ethiopia : A Phenomenological Study. 2021;(June).
  46. Idele P, Gillespie A, Porth T, Suzuki C, Mahy M, Kasedde S, et al. Epidemiology of HIV and AIDS Among Adolescents : Current Status , Inequities , and Data Gaps. 2014;66:144–53.
  47. Melden AI. Willing. *Philos Rev*. 1960;69(4):475.
  48. Tufford L, Newman P. Bracketing in qualitative research. *Qual Soc Work*. 2012;11(1):80–96.
  49. Endriyani L. Self-Concept of People with HIV (PLHIV). 2017;5(3):182–91.
  50. Tran BX, Ho RCM, Ho CSH, Latkin CA, Phan HT, Ha GH, et al. Depression among Patients with HIV / AIDS : Research Development and E ff ective Interventions ( GAP RESEARCH ). 2019;
  51. Abubakar A, Vijver FJR Van De, Fischer R, Hassan AS, Gona JK, Dzombo JT, et al. ‘ Everyone has a secret they keep close to their hearts ’ : challenges faced by adolescents living with HIV infection at the Kenyan coast. *BMC Public Health*. 2016;1–8.
  52. Guide I, Services DHI V. Implementation Guide for Differentiated Service Delivery Models of HIV Services in. 2017;(June).

53. Doat AR, Navab E, Sadat Hoseini AS. Lived Experiences of Adolescent Living with human immunodeficiency virus in Ghana: A Phenomenology Study. *Nurs Open*. 2021;8(1):299–307.
54. Arabia S, Affairs N, Faisal K, Hospital S, Arabia S, Control CI, et al. The lived experience of living with HIV / AIDS in the western region of Saudi Arabia. 2014;215–24.
55. Kalra R, Emmanuel AE. Living with HIV / AIDS : A Qualitative Study to Assess the Quality of Life of Adolescents ( 13- 19 Years ) attending ART Centre of Selected Hospital in New Delhi. 2019;6(1):28–35.
56. Shantanam S, MUELLER. HHS Public Access. *Physiol Behav*. 2018;176(1):139–48.
57. Wekesa E, Coast E. Living with HIV postdiagnosis : a qualitative study of the experiences of Nairobi slum residents. 2013;1–8.
58. Uwamariya J, Nshunguyabahizi M, Nshimyumuremyi JN, Mukesharurema G, Ndayishimiye E, Kamali I, et al. Rediscovering life after being diagnosed with HIV: A qualitative analysis of lived experiences of youth living with HIV in rural Rwanda. *Front Reprod Heal*. 2022;4(November):1–9.
59. Salad AM, Mohamed A, Da'Ar OB, Abdikarim A, Kour P, Shrestha M, et al. Sick and solo: A qualitative study on the life experiences of people living with HIV in Somalia. *HIV/AIDS - Res Palliat Care*. 2019;11:45–53.
60. Yu C, Huang C, Ko N, Tung H, Huang H, Cheng S. The Lived Experiences of Stigmatization in the Process of HIV Status Disclosure among People Living with HIV in Taiwan. 2021;
61. Asuquo SE, Tahlil KM, Muessig KE, Conserve DF, Igbokwe MA, Chima KP, et al. Youth engagement in HIV prevention intervention research in sub-Saharan Africa: a scoping review. *J Int AIDS Soc*. 2021;24(2).
62. Kimera E, Vindevogel S, Kintu MJ, Rubaihayo J, Maeyer J De, Reynaert D, et al. Experiences and perceptions of youth living with HIV in Western Uganda on school attendance : barriers and facilitators. 2020;1–12.

## **Annex-I**

### **Annex-I: Study participants' (youths') information sheet**

#### Information Form

Dear Sir/Madam-----

Greetings! I am Alemu Mitiku a masters of public health student from Jimma University, currently am doing a health study about HIV/AIDS and related health issues, specifically among youths who lived with HIV. The study concerns about supportive conditions, concerns about, related challenges, and sexual behavior and relation of youths, generally which is about lived experiences of those youths who are on HIV treatment follow up for more than one year.

**Aim of the study:** - Its aim is to explore your experience of living with HIV AIDS. I am hoping that the results of this study will assist in understanding experience of youth living with HIV.

**Process of the study:** - The study includes those 15 up to 24 years of age. To be part of this study, you are selected purposively from all other people like you. No laboratory or other measurements are needed; you are only expected to freely discuss with the interviewer. The conversation may take about an hour and for missed information and further clarification you may be re visited as needed in another day based on your willingness.

**Rights of the participants:** - Your participation is fully based on your willingness. As all the conversation is up to your willingness, you are fully entitled to ask, interrupt, skip questions and withdraw from the study any time you like.

**Confidentiality of the study:** - In any means the information you give will not be used for other purpose beyond this study and always be kept in confidential. During the interview, if you are willing, I will use an audio recorder, which means that what we talk about during the interview will be recorded. This is so that I can remember what we talked about. There is no need to mention your name or other identification. The audio tape will be kept locked in a cabinet in my house and only the researcher will be allowed to listen to the audio tape. It will thereafter be destroyed.

**Benefit of the study:** - Being participant of this study by itself doesn't have a direct benefit for you. However this doesn't mean it has no benefit at all. As tried to mention in the beginning your information is helpful for exploring experience living with HIV and improving health care services. At the end of the interview session we will have tea and snack together.

**Risk of the study:** - Your participation has no risks, in all means you are free of any harm and for that the researcher is responsible and accountable.

So considering the above issues I kindly request to put your response in the next page of consent form. If you have any questions you can contact me through the given address.

Thank you!

Alemu Mitiku Etana

Cell phone: - +251917037305

Email: - [moibonmitisha@gmail.com](mailto:moibonmitisha@gmail.com)

Jimma University School of Public Health Department of health behavior and society

## **Annex-II**

### **Study participants' (youths') Informed consent form**

I read/listened the above information and I understood that it is a study that doesn't harm me, is based on only my willingness and promise confidentiality of my responses and no harm and special benefits to me. Accordingly based on my understanding, regarding my participation on the study, without any pressure I reached on the following decision.

- I fully agree to participate
- I do not agree

### **Interviewer**

I assure that I informed and took the consent

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date\_\_\_\_\_

Annex-III

Study participants' (youths') Informed consent form for Audio record

I read/listened the above information and I understood that it is a study that doesn't harm me, is based on only my willingness to audio record and promise confidentiality of my recorded responses and no harm and special benefits to me. Accordingly based on my understanding, regarding my participation on the study, without any pressure I reached on the following decision.

- I fully agree for audio record
- I do not agree for audio record

Interviewer

I assure that I informed and took the consent for audio record

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date\_\_\_\_\_

## Annex-IV

### In-depth Interview Guide

Part one: Participant's Socio demographic characteristics			
SN	Interview guide	Response categories	Skip/remarks
1	Respondent's responsibilities in the house hold	<input type="checkbox"/> Husband <input type="checkbox"/> House wife <input type="checkbox"/> Child <input type="checkbox"/> Other/Specify---	
2	Sex	<input type="checkbox"/> Male <input type="checkbox"/> Female	
3	Age	-----	
4	Religion	<input type="checkbox"/> Muslim <input type="checkbox"/> Orthodox <input type="checkbox"/> Protestant <input type="checkbox"/> Catholic <input type="checkbox"/> Other	
5	Ethnicity	<input type="checkbox"/> Oromo <input type="checkbox"/> Amhara <input type="checkbox"/> Dawro <input type="checkbox"/> Gurage <input type="checkbox"/> Kefa <input type="checkbox"/> Other	
6	Educational status	<input type="checkbox"/> Unable to read and write <input type="checkbox"/> Able to read and write <input type="checkbox"/> Primary 1-8	

		<input type="checkbox"/> Secondary 9-12 <input type="checkbox"/> Diploma and above	
7	Occupation	<input type="checkbox"/> Student <input type="checkbox"/> Daily labor <input type="checkbox"/> Merchant <input type="checkbox"/> Government worker <input type="checkbox"/> Farmer <input type="checkbox"/> House wife <input type="checkbox"/> Unemployed <input type="checkbox"/> Other, specify---	
8	Marital status	<input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed	
9	Source of income	<input type="checkbox"/> Government <input type="checkbox"/> Private	
10	with whom are you living	<input type="checkbox"/> With family <input type="checkbox"/> With relatives <input type="checkbox"/> Live alone	

Interview Guide
Q1: What do you feel about your health as general?
Probe: General, HIV status-when you became aware of it? How you know your status? How long have you been on ART?
Q2: What is your experience of living with HIV?
Probe: Physical effects, illnesses and hospitalizations, medical care and providers, family support, social support, social difficulties any other conditions you had and wish to be done
Q3: What do you think are supportive things for you?
Q4: What do you think are concerning issues for you, regarding to your health and related things?
Q5: Can you tell me any challenge you faced and experience of your coping mechanism?
Probe: From your health status, families, friends, neighbors, community, school, working areas, job, health and clinical appointment
Q6: What is your thought about disclosing your status to your friends or any other person?
Q7: Can you tell me anything to cheer you up when you visit ART clinic?
Q8: What do you think about friendship?
Q9: What is your future life plan?
Probe: What do you think can be done by your family, friends, ART health care provider, case manager, the larger community and government to ensure youth quality of life?
If you have any other concerns you want to share me-----
Summarizing the themes
Thank you for your kind cooperation, I will re visit you based on your willingness for missed or untouched issues if any.

## Annex V

### Amharic version

**አባሪ-I:** የጥናት ተሳታፊዎች (ወጣቶች) የመረጃ ወረቀት

#### የመረጃ ቅፅ

አቶ/ ወዘረት/ሮ-----

ሰላም! እኔ ዓለሙ ምትኩ ከጅማ ዩኒቨርሲቲ የህብረተሰብ ጤና ተማሪ ነኝ በአሁኑ ወቅት ስለ ኤች አይ ቪ ኤድስ እና ተያያዥ የጤና ጉዳዮች በተለይም ከኤችአይቪ ጋር ይኖሩ የነበሩ ወጣቶች ላይ የጤና ጥናት እያደረግሁ ነው። ጥናቱ የሚያመለክተው ደጋፊ

**የጥናቱ አላማ:-** አላማው ከኤችአይቪ ኤድስ ጋር የመኖር ልምድን ማሰስ ነው። የዚህ ጥናት ውጤት ከኤችአይቪ ጋር የሚኖሩ ወጣቶችን ልምድ ለመረዳት ይረዳል ብዬ ተስፋ አደርጋለሁ።

**የጥናቱ ሂደት:-** ጥናቱ ከ15 እስከ 24 ዓመት እድሜ ያላቸውን ያካትታል። የዚህ ጥናት አካል ለመሆን፣ እንደ እርስዎ ካሉ ሌሎች ሰዎች ሁሉ በሆነ መልኩ ተመርጠዋል። ላቦራቶሪ ወይም ሌሎች መለኪያዎች አያስፈልጉም; ከጠያቂው ጋር በነፃነት መወያየት ብቻ ነው የሚጠበቀው። ውይይቱ አንድ ሰዓት ያህል ሊወስድ ይችላል እና ለመለጡ መረጃዎች እና ተጨማሪ ማብራሪያ በፍላጎትዎ መሰረት እንደ አስፈላጊነቱ በሌላ ቀን ሊጎበኙ ይችላሉ።

**የተሳታፊዎች መብት:** - የእርስዎ ተሳትፎ ሙሉ በሙሉ በእርስዎ ፍላጎት ላይ የተመሰረተ ነው። ሁሉም ንግግሮች በእርስዎ ፍላጎት ላይ የሚወሰን እንደመሆኑ መጠን በማንኛውም ጊዜ ለመጠየቅ፣ ለማቋረጥ፣ ጥያቄዎችን ለመዝለል እና ከጥናቱ ለማቆም ሙሉ መብት አለዎት።

**የጥናቱ ምስጢራዊነት፡** - በማንኛውም መልኩ የሚሰጡት መረጃ ከዚህ ጥናት ውጭ ለሌላ ዓላማ አይውልም እና ሁልጊዜ በሚስጥር ይጠበቃል። በቃለ መጠይቁ ወቅት፣ ፍቃደኛ ከሆናችሁ፣ የድምጽ መቅጃ እጠቀማለሁ፣ ይህም ማለት በቃለ-መጠይቁ ወቅት የምንናገረው ነገር ይመዘገባል ማለት ነው። የተነጋገርነውን እንዳስታውስ ነው። የእርስዎን ስም ወይም ሌላ መታወቂያ መጥቀስ አያስፈልግም። የድምጽ ካሴቱ በቤቴ ውስጥ ባለው ካቢኔ ውስጥ ተቆልፎ ይቆያል እና ተመራማሪው ብቻ የድምጽ ካሴትን እንዲያዳምጡ ይፈቀድላቸዋል። ከዚያ በኋላ ይጠፋል።

**የጥናቱ ጥቅም፡** - የዚህ ጥናት ተሳታፊ መሆን በራሱ ቀጥተኛ ጥቅም አይኖረውም። ሆኖም ይህ ማለት ምንም ጥቅም የለውም ማለት አይደለም። መጀመሪያ ላይ ለመጥቀስ እንደተሞከረው መረጃዎ ከኤችአይቪ ጋር የመኖር ልምድን ለመፈተሽ እና የጤና አጠባበቅ አገልግሎቶችን ለማሻሻል ይረዳል። በቃለ መጠይቁ መጨረሻ ላይ ሻይ እና መክሰስ አብረን እንጠጣለን።

**የጥናቱ ስጋት፡** - የእርስዎ ተሳትፎ ምንም አይነት አደጋ የለውም በምንም አይነት መልኩ ከጉዳት ነጻ ነዎት እና ለዚህም ተመራማሪው ተጠያቂ እና ተጠያቂነት ነው። ስለዚህ ከላይ የተጠቀሱትን ጉዳዮች ከግምት ውስጥ በማስገባት ምላሽዎን በሚቀጥለው የፍቃድ ቅጽ ላይ እንዲያቀርቡ በአክብሮት እጠይቃለሁ። ማንኛውም አይነት ጥያቄ ካሎት በተጠቀሰው አድራሻ ሊያገኙኝ ይችላሉ።

አመሰግናለሁ!

አለሙ ምትኩ ኢታና

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**የጅማ ዩኒቨርሲቲ የህብረተሰብ ጤና ትምህርት የጤና ባህሪ እና ማህበረሰብ ትምህርት ክፍል።**

## ANNEX II

### የጥናት ተሳታፊዎች (ወጣቶች) በመረጃ የተደገፈ የስምምነት ቅጽ

ከላይ ያለውን መረጃ አንብቦ/አዳምጬላሁ እና እኔን የማይጎዳ ጥናት እንደሆነ ተረድቻለሁ፣ በፍላጎቴ እና በምላሽ ምስጢራዊነት ላይ የተመሰረተ እና ምንም ጉዳት እና ልዩ ጥቅም የሌለኝ ጥናት ነው። በዚህ መሰረት በጥናቱ ላይ ያለኝን ተሳትፎ በተመለከተ፣ ያለ ምንም ጭና በሚከተለው ውሳኔ ላይ ደረሻለሁ።

- ለመሳተፍ ሙሉ በሙሉ ተስማምቻለሁ
- አልስማማም።

### ጠያቂው

የፈቃዱን ስም እንዳሳወቅኩና እንደወሰድኩ አረጋግጣለሁ፡

ስም \_\_\_\_\_

ፊርማ: \_\_\_\_\_

ቀን \_\_\_\_\_

### ANNEX III

#### የጥናት ተሳታፊዎች (ወጣቶች) በመረጃ የተደገፈ የስምምነት ቅጽ ለድምጽ መዝገብ

ከላይ ያለውን መረጃ አንብቤ/አዳምጭዋለሁ እና እኔን የማይጎዳ ጥናት እንደሆነ ተረድቻለሁ፣ በድምፅ ቀረጻ ለማድረግ ያለኝን ፍላጎት ብቻ እና የተቀዳው ምላሼን ምስጢራዊነት ቃል በመግባት እና ለእኔ ምንም ጉዳት እና ልዩ ጥቅም የለም። በዚህ መሰረት በጥናቱ ላይ ያለኝን ተሳትፎ በተመለከተ፣ ያለ ምንም ጭና በሚከተለው ውሳኔ ላይ ደረሻለሁ።

- ለድምጽ ቅጂ ሙሉ በሙሉ እስማማለሁ
- በድምጽ ቀረጻ አልስማማም።

ጠያቂው

ለድምጽ መዝገብ ስምምነቴን እንዳሳወቅኩ እና ፈቃዱን እንደወሰድኩ አረጋግጣለሁ፡

ስም \_\_\_\_\_

ፊርማ: \_\_\_\_\_

ቀን \_\_\_\_\_

Annex-IV

ጥልቅ የቃለ መጠይቅ መመሪያ

ክፍል አንድ: የተሳታፊ ሶሺዮ ስነ-ሕዝብ ባህሪያት			
ተ/ቁ	የቃለ መጠይቅ መመሪያ	የምላሽ ምድቦች	ዝለል/ አስተያየቶች
1	በቤቱ ውስጥ ያሉ የተጠሪ ኃላፊዎች ይያዛሉ	<input type="checkbox"/> ባል <input type="checkbox"/> የቤት ሚስት <input type="checkbox"/> ልጅ <input type="checkbox"/> ሌላ/ይግለጹ ---	
2	ጾታ	<input type="checkbox"/> ወንድ <input type="checkbox"/> ሴት	
3	ዕድሜ	-----	
4	ሃይማኖት	<input type="checkbox"/> ሙስሊም <input type="checkbox"/> ኦርቶዶክስ <input type="checkbox"/> ፕሮቴስታንት <input type="checkbox"/> ካቶሊክ <input type="checkbox"/> ሌላ	
5	ብሄር	<input type="checkbox"/> ኦሮሞ <input type="checkbox"/> አማራ <input type="checkbox"/> ዳውሮ <input type="checkbox"/> ጉራጌ <input type="checkbox"/> ከፋ <input type="checkbox"/> ሌሎች	
6	የትምህርት ደረጃ	<input type="checkbox"/> ማንበብና መጻፍ አለመቻል <input type="checkbox"/> ማንበብና መጻፍ አለመቻል 57 <input type="checkbox"/> የመጀመሪያ ደረጃ 1-8 <input type="checkbox"/> ሁለተኛ ደረጃ 9-12 <input type="checkbox"/> ዲፕሎማ እና ከዚያ በላይ	

7	ሥራ	<input type="checkbox"/> ተማሪ <input type="checkbox"/> የቀን ሰራተኛ <input type="checkbox"/> ነጋዴ <input type="checkbox"/> የመንግስት ሰራተኛ <input type="checkbox"/> አርሶ አደር <input type="checkbox"/> የቤት ሚስት <input type="checkbox"/> ስራ አጥ <input type="checkbox"/> ሌላ ይግለጹ ---	
8	የጋብቻ ሁኔታ	<input type="checkbox"/> ያላገባ <input type="checkbox"/> ያገባ <input type="checkbox"/> የተፋታ <input type="checkbox"/> ባል የሞተባት	
9	የገቢ ምንጭ	<input type="checkbox"/> መንግስት <input type="checkbox"/> የግል	
10	ከማን ጋር ነው የምትኖረው	<input type="checkbox"/> ከቤተሰብ ጋር <input type="checkbox"/> ከዘመዶች ጋር <input type="checkbox"/> ብቻህን	



## ANNEX VI

### Afaan Oromoo Version

<b>Kutaa Lammaffaa: Seenaa Fayyaa dargaggoota HIV waliin jiraatanii.</b>
<b>1. Haala fayyaa keessanii/keetii natti himuu dandeessu/ssaa?</b>
Qorannoo Dabalataa: Waliigalaa, HIV waliin jiraachuu akkamiin ilaalta? HIVn dhiiga keessa jiraachuu akkamiin barte? qoricha farra HIV fudhachuu erga eegalte waggaa meeqa?
<b>2. Mudannoo fi muuxannoon HIV waliin jiraachuu keen walqabatee si mudate haalaan naaf gooduu dandeessaa?</b>
Qorannoo Dabalataa: miidhaa qaamaa si qaqqabe, wal'aansaaf dhaabbata fayya ciistee yoo bekte, wal'aansa fayya siif kenname, Deeggarsa Maatii, Deeggarsa Hawaasummaa, Rakkoolee Hawaasummaa Haalawwan Deeggarsaa biroo kamiyyuu kan siif taasifamee fi gara fuuladuraattis akka siif tasifamu kan feetu.
<b>3. Gargaarsa adda addaa at argattee beektuufii gargaarsi at yoo dargaggootaaf kenname gaariidha jettu maali?</b>
<b>4. HIV waliin jiraachuu keen walqabatee wanti si yaadessuu maali?</b>
<b>5. Yeroo qormaatni ykn haalli rakkisaan si mudatu tooftaa akkamiin mo'atta ykn damdamatta?</b>
Qorannoo Dabalataa: Fakkeenyaaf mee muuxannoo fi mudannoo yaadattu kamiyyuu natti himuu dandeessaa?
<b>6. Waa'ee fayya kee fi HIV waliin jiraachuu kee, akkamitti fi eenyuun mari'achuu filattu/tta?</b>
<b>7. Yeroo dhaabbata kenninsa tajaajila yaala HIV deemtu waan si gammachiisu natti himuu dandeessaa?</b>
<b>8. Yaadni fi muuxannoon kee waa'ee hiriyyummaa saal-qunnamtii maali?</b>
<b>9. Karoorri jireenya kee gara fuula duraa maali?</b>
Qorannoo Dabalataa: Haala jireenya dargaggoota HIV waliin jiraatan foyyessuu dhaaf: maatii, hiriyyoota, ogeessa fayyaa ART, hawaasa bal'aa fi mootummaan maal gochuu qaba jettanii/ttee yaaddu/dda?
Yaada biraa yoo qabaatte naaf gooduu dandeessa-----
Gudunfaa.
Tumsaafi gargaarsa gaarii naa taasiftaniif galatoomaa, yaada irraanfattan yoo qabaattan ykn dhimma ijoo hin tuqamiin hafee yoo jiraate fedhii keessan irratti hundaa'uun irra deebiin waliin irratti mari'achuu dandeenya.

## **Dabalata-I/ Annex-I:**

Annex-I: Waraqaa Odeeffannoo Hirmaattota Qorannichaa (Dargaggoota)

Unka Odeeffannoo .

Kabajamaa Sir/Maadaam-----

**Nagaa!** Ani Alemu Mitiku barataa fayyaa hawaasaa Yunivarsiitii Jimmaa irraa kan masters ta'e, yeroo ammaa waa'ee HIV/AIDS fi dhimmoota fayyaa kanaan walqabatan, addatti dargaggoota HIV waliin jiraatan gidduutti qorannoo fayyaa hojjechaa jira. Qorannoon kun yaaddoo haala deggersaa, yaaddoo, qormaata walqabatee, fi amala saalqunnamtii fi hariiroo dargaggoota, walumaa galatti waa'ee muuxannoo jiraatame dargaggoota wal'aansa HIV irra jiran waggaa tokkoo oliif hordoffii.

**Kaayyoo qorannichaa:** - Kaayyoon isaa muuxannoo AIDS HIV waliin jiraachuu kee qorachuudha. Bu'aan qorannoo kanaa muuxannoo dargaggoota HIV waliin jiraatan hubachuuf akka gargaaru abdiin qaba.

**Adeemsa qorannichaa:** - Qorannoon kun kanneen umuriin isaanii waggaa 15 hanga waggaa 24 ta'e of keessatti qabata. Qaama qorannoo kanaa ta'uuf, namoota akka keetii hunda keessaa kaayyoodhaan filatamta. Laaboraatoorii ykn safartuuwwan biroo hin barbaachisu; Gaafatamtoota waliin bilisaan mari'achuu qofatu si irraa eegama. Haasaan gara sa'aatii tokkoo fudhachuu danda'a, odeeffannoo darbee fi ibsa dabalataaf fedhii kee irratti hundaa'uun guyyaa biraatti akka barbaachisummaa isaatti deebitee daawwatamuu dandeessa.

**Mirga hirmaattootaa:** - Hirmaannaan kee guutummaatti fedhii kee irratti hundaa'a. Haasaan hundi fedhii kee waan ta'eef, yeroo jaallattutti gaaffii gaafachuu, addaan kutuu, darbuu fi qo'annoo keessaa ba'uuf guutummaatti mirga qabda.

**Iccitii qorannichaa:** - Karaa kamiinuu odeeffannoon ati kennitu qorannoo kanaan ala kaayyoo biraatiif kan hin fayyadamne yoo ta'u yeroo hunda iccitii ta'ee kan turu ta'a. Yeroo gaaffii fi deebii kanaatti yoo fedhii qabaattan sagalee waraabu nan fayyadama, kana jechuun yeroo gaaffii fi deebii sanaa wanti nuti dubbannu ni waraabama jechuudha. Kunis waan haasofne akkan

yaadadhuuf. Maqaa kee ykn eenyummaa kee kaasuun hin barbaachisu. Teeppiin sagalee mana koo keessa kaabinee keessatti cufamee kan turu yoo ta'u, qorataa qofatu teeppii sagalee dhaggeeffata. Sana booda ni diigama.

**Faayidaa qorannichaa:** - Hirmaataa qorannoo kanaa ofuma isaatiin faayidaa kallattiin siif hin qabu. Haa ta'u malee kun tasumaa faayidaa hin qabu jechuu miti. Akkuma jalqaba irratti eeruuf yaale odeeffannoon keessan muuxannoo HIV waliin jiraachuu fi tajaajila eegumsa fayyaa fooyyessuuf gargaara. Xumura gaaffii fi deebii irratti shaayii fi nyaata salphaa waliin nyaanna.

**Balaa qorannichaa:** - Hirmaannaan kee balaa hin qabu, karaa hundaan miidhaa kamiyyuu irraa bilisa ta'uu kee fi sanaaf qorataan itti gaafatamummaa fi itti gaafatamummaa qaba.

Egaa dhimmoota armaan olii ilaaluun deebii kee bifa hayyamaa fuula itti aanu keessatti akka kaa'u gaarummaadhaan gaafadha. Gaaffii yoo qabaattan karaa teessoo kenname na qunnamuu dandeessu.

Galatoomaa!

Alemu Mitiku Etana .

Bilbila harkaa: - +251917037305

Email: - [moibonmitisha@gmail.com](mailto:moibonmitisha@gmail.com)

Yuunivarsiitii Jimmaa Mana Barumsaa Fayyaa Hawaasaa Kutaa Fayyaa fi Hawaasa

## **Dabalata- II.**

Unka Hayyamaa Hirmaattota Qorannichaa (Dargaggoota)

Odeeffannoo armaan olii kana dubbisee/hubadhe qorannoo na hin miine, fedhii koo fi iccitii deebii koo qofa irratti kan hundaa'e ta'uu isaa fi miidhaa fi faayidaa addaa naaf hin qabne ta'uu isaa hubadheera. Haaluma kanaan hubannoo koo irratti hundaa'uun, hirmaannaa koo qorannicha irratti, dhiibbaa tokko malee murtoo armaan gadii irra ga'e.

hirmaachuuf guutummaatti walii gala .

Ani walii hin galu.

### **Raawwataa Af-gaaffii**

Ani Raawwataan Af-gaaffii akkan odeeffamee fi hayyama fudhadhe nan mirkaneessa .

Maqaa: \_\_\_\_\_

Mallattoo: \_\_\_\_\_

Guyyaa \_\_\_\_\_

### **Dabalata-III**

Unka hayyama hirmaattoota (dargaggoota) kan galmee sagaleef ittin walii galamu.

Odeeffannoo armaan olii kana dubbisee/hubadhe qorannoo na hin miine ta'uu isaa, fedhii koo galmee sagalee irratti kan hundaa'ee fi deebii koo galmaa'ee fi miidhaa fi faayidaa addaa kan hin qabne ta'uu isaa hubadheera. Haaluma kanaan hubannoo koo irratti hundaa'uun, hirmaannaa koo qorannicha irratti, dhiibbaa tokko malee murtoo armaan gadii irra ga'era.

- Galmee sagaleef guutummaa guututti walii nan gala.
- Galmee sagaleef walii hin galu.

### **Raawwataa Af-gaaffii**

Ani Raawwataan af-gaaffii odeeffannoo fi hayyama galmee sagalee akkan fudhadhe nan mirkaneessa.

Maqaa: \_\_\_\_\_

Mallattoo: \_\_\_\_\_

Guyyaa \_\_\_\_\_

## Code List

Code-Filter: All

---

HU: Alemu Atlas  
File: [C:\Users\MOIBON\Desktop\Alemu Atlas.hpr7]  
Edited by: Super  
Date/Time: 2022-08-19 22:14:33

---

adaptation  
adverse effect  
advice  
afraid  
age  
alarming  
angry  
Anxiety about future life  
appontement  
aspiraton  
attempt to diclose  
attending  
attituide to HIV  
avoidance  
Avoidance  
award  
bad exprience  
bad feeling  
bad story  
being accepted  
being ashamed  
being busy  
being careless  
being free  
bisot  
blamed  
Boredom of drug dependency  
boring things  
break privacy  
Challenges faced by youths living with HIV  
challenging life  
church  
clarifying  
client load  
clinic care  
Clinic care and support  
clinic challenge  
clinic schedule  
close friend  
cofidentiality  
comfort  
community awernse  
complexity

concerns  
confidence to ARV  
confused  
coping  
Coping strategy of YLWH  
counselling  
couple  
curage  
current life  
delighted  
dependancy  
disagree  
disappointing  
disclosure to other  
discomfort  
discordant couple  
discrimination  
Disinformation  
disinterest  
dislike clinic  
dislike condom  
divorce  
doubt about sexual relation  
drug regimen  
duration of PSSG  
duration of relation  
early family loss  
Escape Avoidance  
failed relation  
faithfulness  
family defficulties  
family disclosure  
family loss  
Family support  
fear  
Fear of being sick  
Fear of forming family  
Fear of having HIV  
Fear of revealing one's own status  
Feeling of guilty  
feeling of youth about future life  
field of study  
forget  
frequency  
frustration  
fully disclosed  
futuraity  
gender  
good support  
guilty  
hate ARV  
Healt education  
health issue discussion

health worker disclosure  
help  
hiding  
holly sprit  
honest  
Hope  
humanity  
I am highly excited when I was..  
I got support from ART clinic  
ignorance  
Illegal disclosure  
ilness  
impact  
insecured  
insuffient support  
interest  
irrigular  
job  
job opportunity  
joking  
kids  
knowledge  
lack of confidence  
lack of knowledge  
Lack of meaningful sexual relation  
lack of social support  
leaving residency areas  
level of education  
LIVED EXPRIENCE OF YOUTHS LIVING WITH HIV  
living with  
Low self-esteem  
marital status  
medication  
misinformation  
missed opportunity  
negative impact  
negative self image  
new relation  
NGO support  
not aware  
not curative  
occupation  
oppportunity  
pain  
parent care  
parent health  
Participants background  
peer encouragement  
peer support  
period  
poor attention  
practice of sex  
prevantion

Prevarication  
privacy for drug intake  
programatic  
promise  
Psychological experience of YLWH  
QACC  
recall  
reaction to serostatus  
refraction on HIV  
regret  
rejection  
religion  
Religiosity  
Religion  
reluctant  
remain silent  
sake of employment  
sake of support  
sake of treatment  
school challenges  
searching sexual relations  
secret  
sedentary  
seems ok  
Self-concealment  
Self avoidance  
self care  
Self determination  
self devaluation  
self disclosure incident  
self disclosure thought  
self image  
sexual relation  
sexual relation plan  
shocking  
side effect  
social discrimination  
social stigma  
Social stigma and discrimination  
start  
start ART  
stigma  
stress  
suicidal  
support from ART clinic  
suspension  
sustainablity  
teacher counselling  
teachers misbehavior  
thought of future life  
threat  
time remainder  
training

traumatization  
treatment  
unprotected intercourse  
unwillingness to disclose  
Use of condom  
visuality problem  
vomiting  
vulnerablity  
with my mother, grandfather an..  
woman affairs  
worrying about sexual relation  
yeaha but we are not together  
youth club  
Youth cope up strategy  
Youth expectation  
Youth future life plan  
youth perception  
youth responsiblity  
Youths' source of supports

## Annex-VI: Lived experiences of youths living with HIV 2022; Code book

<b>code</b>	<b>Description</b>	<b>Quotes</b>
<b>Personal info</b>	Description of age, sex, education, occupation, marital status	' I am 18 years old and 11 <sup>th</sup> grade a student'
<b>Family lose</b>	Mother and father's health	my mother has died
<b>Living with</b>	Description of living condition and with whom one lives	'I live with my grand mother
<b>Health feeling</b>	Any description of general health status	Glory to GOD, I am healthy' after I started medication
<b>HIV self disclosure</b>	Description of how they knew their status	I knew my status incidentally'
<b>disclosure</b>	Description of disclosing HIV status to others	I kept to my heart, I don't want to tell for other unless special issue
<b>Reaction to sero status</b>	Description of any reaction to knowing their sero status	I cried when told me as I have HIV
<b>Experience of ARV drug intake</b>	Description of taking ARV drug	I have being taking ARV drug since my childhood'
<b>Family support</b>	Description of any support from families	'I have a family who supports me....'
<b>ART clinic care &amp; support</b>	Description of approaches and services from ART clinic and health care providers	"The care providers have a well coming face and are kind...."
<b>Clinic services</b>	Any clinic services in terms of access, quality, and adequacy	"I can get the service I need any time..."
<b>Social support</b>	Any positive approach and support from friends, neighbors, teachers...	"My friends are like my family; they understand my feeling and support me in many things..."
<b>Peer group</b>	Description of any groups found and any experience related with	'we have a group of HIV positive youths
<b>Challenge of r/ship</b>	Description of any things that describe low self esteem	I have boyfriend previously but now a day is failed
<b>Fear of Social stigma</b>	Any description of thinking about stigma from different sides	"I can't take my drugs if people are around me...."
<b>Attitude to HIV</b>	Description of any attitude to HIV	community's attitude to HIV positives is not good'
<b>Changing things</b>	Description of suggested things that needs improvement	If said ' I wish if community's awareness is changed'
<b>Reaction to HIV</b>	Description of reactions to HIV	'I feel bad for HIV
<b>Responsibility</b>	Description of role and responsibilities in HIV prevention	'we should take care of others'
<b>Risky behavior</b>	Description of any things that reveal risky behavior	I forget my pill when I drink alcohol
<b>Drug intake</b>	Any description related with drug's taste,	"The drug is uninteresting and

	load, timing...	has bad taste....”
<b>Sexual r/ship concern</b>	Any description of thinking about missing, having and planning to form a family	“I wish to have a family but no one is interested to be romantic with you....”
<b>self-disclosure thought</b>	Any description of disclosing or not of self-status	“I wish to disclose my status but I fear....”
<b>Loneliness</b>	Any description of feeling loneliness and why	“I usually stay alone...”
<b>Stressful things</b>	Description of any stressful conditions for them	‘I worries if I fails in my education’
<b>Threats</b>	Description of any threatening things	‘my threat is if getting job needs medical certificate’
<b>Family loss</b>	Any family loss and challenges related with	“I missed family member
<b>Economical issues</b>	Any description of income, shelter and other insecurity	“I can’t get enough support....”
<b>Clinic support</b>	Any description related with clinic support and care	“I got many support from ART clinic ...”
<b>Disclosure to others</b>	Any description of challenges related with not disclosing self-status	If said as “I may not get other medical services at other clinics without disclosing my status
<b>Barriers to visit ART clinic</b>	Any description of barriers to visit ART clinic issue	“I am not comfort when a person seeing me while I collect my medication...”
<b>Past Sexual relation</b>	Any description of experiences related to sex	“I had had a friend and we had sex with condom
<b>Current Sexual relation</b>	Any description of current sexual relation status	“I have no sexual experience now...”
<b>sexual relation plan</b>	Description of what is the thought and plan of sexual relation	“I wish to have a boyfriend.....”
<b>sexual relation concern</b>	Description of what the sexual relation should be	“I believe we should be care full of not to infect others...”
<b>Future life plan</b>	Description of future plan in life	‘I want to be a doctor
<b>Things to do</b>	Description of what they wish to be done for them	‘ I wish innovative ARV drug of injection form”
<b>health issue discussion</b>	Description of any discussion about self-health condition with any one	‘ I talk with my friends about my health’
<b>Boring things</b>	Description of any things that are boring	‘ I am boredom of taking drugs’
<b>Loss of hope</b>	Description of any things that reveal loss of hope	‘ I have no hope’
<b>Low self-</b>	Description of any things that reveal low	I fear to interact with my friends

<b>esteem</b>	self esteem	in school
<b>Self concealment</b>	Description of any things that reveal low self esteem	I conceal any negative information about me
<b>Coping mechanism</b>	Description of any things that reveal coping the problem	I pray the GOD to be free from this virus
<b>Escape avoidance</b>	Description of any things that escape avoidance	I escaped any moment that expose me to disclose my status
<b>Job opportunity</b>	Description of any things that reveal job opportunity	Am a case manager
<b>Regret</b>	Description of any things that reveal regret	I blame that day of I participated in bad deeds
<b>Daily work</b>	Description of any things that reveal daily activity to live	Am a carter and I piercing a belt at night
<b>Challenge related status</b>	Description of any things that reveal challenge among sero status	My friend ignore me after he/she know my status
<b>Self-devaluation</b>	Description of any things that reveal self-devaluation	When I compare myself with HIV free youth I scarce