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SCHOOL OF NURSING AND MIDWIFERY
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LIVED EXPERIENCE OF ADOLESCENTS LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS AT TIKUR ANIBESA SPECIALIZED HOSPITAL, ETHIOPIA: A PHENOMENOLOGICAL STUDY

PRINICIPAL INVESITGATOR: MIHRET FIKREYESUS (BSCN)

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BY: MIHRET FIKREYESUS (BSc.)

PEDIATRICS AND CHILD HEALTH NURSING TRACK

MAJOR ADVISOR: Dr. AMSALE CHERIE (MSC, PHD)

CO-ADVISOR: FIKRTEMARIAM ABEBE (BSC, MSC)

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COLLEGE HEALTH SCIENCE

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This thesis by **Mihret Fikreyesus (BSc)** is accepted in its present form by the board of examiners as satisfying thesis requirement for the degree of masters in child health nursing on a title **“Lived Experience of Adolescents Living with Human Immunodeficiency Virus at Tikur Anbesa Specialized Hospital, Ethiopia: A Phenomenological Study”**

INTERNAL EXAMINER:

1. Dr. Rajalakshimi Murugan (PhD) _______________ ______________

Name Signature Date

RESEARCH ADVISORS:

1. DR. Amsale Cherie (PhD) ____________________ __________________

Name of Major Advisor Signature Date

2. Mrs. Fikrtemaria Abebe (MSc.) ____________________ __________________

Name of Co-Advisor Signature Date

DEPARTMENT HEAD

_________________________ _____________ ______________

NAME SIGNITURE DATE

DECLARATION PAPER

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Mihret Fikreyesus (BSc**)** Signature: _________Date_____________

RESEARCH ADVISORS:

1. DR. Amsale Cherie (PhD) __________________ ________________

Name of Major Advisor Signature Date

2. Mrs. Fikrtemaria Abebe (MSc.) __________________ ________________

Name of Co-Advisor Signature Date

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ABBREVIATIONS AND ACRONYMS

AIDS-Acquired Immune Deficiency Syndrome

ADLWH- Adolescents living with HIV

ART-Anti-Retroviral Therapy

CD-4-Cluster of Differentiation 4

HIV-1-Human Immunodeficiency Virus 1

HIV-Human Immunodeficiency Virus

NGO-Non-Governmental organization

RNA-Ribose- Nucleic Acid

SRH-Sexual Reproductive Health

STD-Sexually Transmitted Disease

UNICEF-United Nations International Children Emergency Fund

WHO-World Health Organization

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ABSTRACT

Background: Ethiopia has a considerable number of adolescents who acquired HIV through vertical and horizontal transmission. An adolescence living with HIV has various concerns and their life is surrounded by embarrassment, dilemma, loneliness, defamation, rejection and fear of their status known by others. However the life experience of adolescents living with HIV is not well explored. The present pace of research concerning to adolescents with HIV experience is still not enough comparing with the needs of adolescents living with HIV. Therefore, this study was conducted to explore the lived experience of adolescents living with HIV. **Methods:** A phenomenological qualitative study was conducted from Februarys 8-march 8 2021 at Tikur Anbesa specialized hospital Addis Ababa, Ethiopia among 18 study participants who were from 10-19 years who had acquired HIV horizontal or vertical transmission. They were chosen by purposive sampling technique. A semi-structured open ended interview guide was used for collecting data. The interview was audio recorded, transcribed and translated to English by the principal investigator. The translated data was imported to Atlas Ti 8 software for coding and categorization. To assure trustworthiness the principles which are basic were applied. Finally results were summarized using thematic analysis. **Result:** The participants in this study expressed living with HIV have several challenges. Feelings of loneliness, being sad and angry were reported. After disclosure benefits were gotten that helped to increase adherence of drug and they understood about their disease. The adolescents don't tell their status to others because of fear of stigmatization. Most of the participants perceived a positive spouse for the future so that to understand and help with each other. They would like it if there is no stigmatization among the society and wanted more advanced medication. Majority of participants have bright future about their life and some wants to have their own family in the future. **Conclusion and recommendations:** In this study it is revealed adolescents who are living with HIV have numerous challenges and concerns. Therefore multiple interventions at individual, community and organizational levels are suggested to support and satisfy the health requirements of the adolescents.

Keywords: Adolescents, Living with HIV, Lived experiences, Phenomenology

1. INTRODUCTION

1.1 Background of the study

One of the viruses that target the Cluster of Differentiation 4 cells of the immune system is the human immune deficiency virus .These CD4 cells help the body to respond to infection that may occur and HIV reproduces in these cells. If a combination of antiretroviral drug is not given the virus will weaken the immune system resulting in infection and disease(1).

Adolescence is the phase of life between childhood and adulthood, from ages 10 to 19. Adolescents experience fast physical, cognitive and psychosocial growth. This affects how they feel, think, make choices, and relate with everyone(2). It is the year between beginning of puberty and the formation of social independence(3). To grow and develop in good health, adolescents essential information, including age-appropriate comprehensive sexuality teaching; chances to mature in life skills; health services that are suitable, equitable, suitable and actual; and safe and helpful surroundings(2).

Ethiopia has numerous adolescents who are living with HIV (4). Some of them acquired the infection vertically from their mothers. An adolescent with prenatally acquired HIV is a person who gets the virus from his/her parents and lives with it though out his/her life(5). It additionally requires an alternate treatment and support different from adults. There are also some adolescents who acquire the virus horizontally through sexual intercourse or other transmission ways in their childhood(6) .

An adolescence living with HIV has various concerns and their life is surrounded by embarrassment, dilemma, loneliness, defamation, rejection and fear of their status known by others. This creates a negative feeling that having HIV is dishonorable. Adding to these adverse relationships with adolescences who are struggling to create their personality, the contrary reaction from individuals to HIV will prompt self-stigmatization which makes sensation of contrast and confinement. Additionally being less esteemed than their companions happens. Teenagers who grow up with HIV, the infection is firmly associated with their wisdom of what their identity is. In any case, inferable from disparagement they will stay quiet about part of themselves which creates pressure(7).

The current speed of researches concerning to adolescents with HIV experience is as yet insufficient contrasting with the needs of Adolescents living with HIV. Consequently it is fundamental to evaluate and assess coordinated arrangements that will inform strategy and improve life experience of ADLWH (8). Teenagers also need to be supported towards the significance and dangers of revealing their HIV status to others when, how and to whom(7).

1.2 Statement of the problem

HIV/AIDS remains one of the concerns of the global community. HIV has killed 33 million people in the world until 2020(1). Approximately 38 million people in the world were infected with HIV/AIDS in the year 2019 in which 7 million are newly diagnosed. From which 95.2% are adults and 4.8% were children less than 15 years old. AIDS related deaths have been recorded as 690,000 people in the year 2019(9).

The second cause of death for adolescents in the world is HIV. Recently in African region HIV deaths have been increasing in adolescent age group while deaths related to HIV are decreasing in other age groups. By investing in the health of adolescents, we can see improvements in child health(10).

In the year 2012 35.3 million people were living with HIV of which 2.1 million were adolescents between ages 10-19 years old. This number remained the same until the year 2017. This number includes both adolescents who developed HIV from their mother through birth or breastfeeding and those who acquired it from exposed sex or by sharing non-sterile injection equipment. 82% of adolescents were living in sub-sahran countries(11).

According to WHO from 102.4 million people living in Ethiopia 710,000 are living with HIV/AIDS in 2016(4).From which number of children infected was 62,000 and number of women was 400,000 from the total population infected with HIV/AIDS(4).

Over the next years, infants and young children diagnosed with HIV will become adolescents. While some of them are diagnosed, knew their status and are on antiretroviral drugs. But in other hand some have not been diagnosed. Altogether of them will be challenged in physical, emotional and social tasks of adolescences with living HIV and preventing further transmission(12).

Reduced adherence and commitment in clinical care during adolescence is common. The belief that HIV is a killer disease with narrow chances leads to becoming fatalistic. Furthermore risk taking behavior which is common in adolescents may be more extreme than their respective peers who are HIV negative. Consequently they are low self-stemmed and don’t see a future for themselves(7).

Recently HIV programs have acknowledged adolescents as a critical age group. Also adolescents continue to be part of the services given across the HIV cascade. These adolescents have less access to coverage of ART and also have higher loss to follow up, poor adherence and increased needs for psychosocial, sexual and reproductive health services(13).In a study done in Ethiopia, on 2058 participants of which 52.1% were adolescents revealed that adolescent (15-19 years) had the higher risk of lost to follow up compared to children (0-9 years)(14).

Similarly ADLWH will become sexually active and they may transmit the virus to others and result in a second generation of children to which HIV is transmitted to their off springs. Most researches done on HIV infected adolescents are concerned to epidemiology of HIV infection among adolescents rather than their life experience living with HIV(15).

In researches done on HIV, adolescents have not gotten the essential attention. The present facts are not enough for developing and planning programs that are particular to adolescents as there is a gap in age and sex-disaggregated data. Still researches and assessments on HIV services avoid adolescents because of gaining assent or challenge of assembling detailed documents from paper centered system(16).

Significant effort is still needed to understand what is good for adolescents living with HIV/AIDS. More researches are also needed to give feedbacks on initiation and directed involvement for adolescent HIV policy. In this result of adolescents and targets of AIDS free generation by 2030 will occur(17).

1.3 Significance of the study

Ethiopia is one of the countries with high number of adolescents infected with HIV. Assessing the lived experience of adolescents living with HIV will help in finding out where we need to give attention for satisfying their health requirements. Also this research will support to identify the knowledge gap and offer unique facts on their needs which will help in developing health policies applicable to them. Likewise this study will enable health care service providers, key stake holders, program managers and investigators to implement more fixated services on perspective of adolescents living with HIV/AIDS. Such understanding can be practical to other adolescent living with HIV in Ethiopia and other countries which has the same similar culture and widespread. So this research will try to identify the lived experience of ADLWH from them and further research can be follow-on from the findings.

2. Literature review

Assessing different types of literatures, here are issues presented relating to adolescents living with HIV/AIDS. This literature review will cover general descriptions about HIV/AIDS, HIV and Adolescents, expressions and feelings of adolescents living with HIV towards HIV, disclosure of status to adolescents and other people, SRH of adolescents, stigmatization among HIV positive adolescents, coping strategies applied by adolescents while living with HIV/AIDS, future plans and perception about support services they need.

2.1 General description of HIV/AIDS

HIV was first diagnosed in United States of America in 1981 who were all homosexual men after developing Pneumocystis pneumonia. The editorial note stated this disease occurred in severely immunosuppressed patients. It proposed the reason related to being all of them homosexuals may be related to their homosexual lifestyle and a disease contracted from sexual contact. It also suggested the risk of "cellular immune dysfunction" related to exposure that prompts individuals to pneumocystis and candiasis(18).

AIDS was suspected it is caused by an infectious agent which is the retrovirus now known as human immunodeficiency virus(19). Even though Retroviruses were first recognized in the late 1980s, their evolutionary source, geographic dissemination, occurrence, natural history and pathogenesis in natural and non-natural host has been known recently(20).

After about 30 years HIV's identification, it has affected 60 million people in the world and caused 25 million deaths(21).

2.2 HIV/AIDS and Adolescents

Adolescence is the crucial stage of human growth. Changes that occur in biological and psychosocial behavior during the teenager age affect every single features of adolescent's life. Chronic illnesses which are examples of major health problems affect adolescent's physical and mental development(10).

A research done among 38 countries in developing countries discovered different facts. In 10 out of 20 countries of sub-sahran African countries 30% of young females stated taking higher risk sex in the previous 12 months. In Ethiopia it was reported as ten percent. Also in the study, young female described having sexually transmitted disease or symptoms of STI in the preceding year more than young males. Associated with this in most sub-Saharan Africa countries,10% of young females and males have never ever been tested for HIV(16,22,23).

A description cross sectional study done among 328 adolescents with HIV/AIDS in Cambodia stated most adolescents(82%) become HIV infected vertically from their mother and these adolescents were on treatment for 8.4 years in average. The other group which consists 18% did not know where they get the infection(24).

Reaching youngsters at an impressionable age before they become sexually active can lay the foundations for a responsible lifestyle, including sex and marriage. Adolescent HIV/AIDS is an epidemic with difference and its control needs to be adolescent specific(25).

Adolescents living with HIV face different challenges while accepting and treating their disease. These adolescents are in rejection, terrified, mislead or lack family or community support. Therefore, these adolescents profit from psychotherapy services and supportive care. Giving care for adolescents has multifaceted in which adolescents are not the same. But they are the same in a manner they all require sensitive, socially and developmentally proper attention. And health care providers must treat adolescents as a whole with consideration in financial, emotional and family environment(25).

2.3. Lived experience of adolescents living with HIV/AIDS.

2.3.1 Expressions and feelings of HIV infected adolescents towards HIV

Various researches done worldwide show there are diverse feelings and expressions of living with HIV among adolescents. In a qualitative research done in South Africa among adolescents who are living with HIV indicated HIV as negative aspects of life. They reported it is painful both emotionally and physically. Also since the disease is life long, they expressed it as a stressful factor(26). Also another study done in Swaziland revealed adolescents who are living with HIV feared death when they were first told about their HIV status. But through time they accepted it and tried to incorporate HIV into their lives(27).

Additional research done in Tanzania and Brazil also reported adolescents living with HIV felt different from their equals specifically this difference occurs in taking lifelong medication(28,29) and also feel hopelessness. Sadness, blaming self and feelings of isolation were also expressed(29). An additional qualitative research in Tanzania also reported they feel shame and bitterness because HIV is considered as a sexually transmitted disease primarily(30).

Depressive emotional states, bad temper, anxiety, stress, family fights and feelings of anger triggered by not accepting the infection were also associated with missed doses or drug treatment discontinuation associated with poor adherence and stopping medication(28).

However there are also some who does not feel anything and take the disease as normal as they meet people like them(29). Also participants who were in Brazil expressed they consider themselves as a normal person. They compare themselves to those adolescents who are equal to them and realize nothing blocks them to live like them. However this is guaranteed by the support of the health workers and they have to also keep their status a secret(28).

In contrast some adolescents are happy and remain positive towards HIV when there are strong family relationships. Those adolescents who don't have family support felt anxiety about their life(26).

2.3.2. Disclosure of HIV status to HIV infected adolescents

Revelation of HIV status to children in a family is a troublesome occurrence for both the person who disclose it and for the child who is told. Different studies also show there is a decreased rate of disclosure. Majority of young adolescents living with HIV doesn't know their status(31–34). Researches done in Ethiopia also display there is low rates of HIV disclosure to HIV infected adolescents. A study done in Addis Ababa in 390 children and caregivers, only seventeen percent knew their status. The caregivers believe the correct age for disclosure is 14 years old (33). In the same place study another identified sixteen percent of HIV positive children knew their status from the whole(34).

Another study in Dire Dawa showed higher rates of HIV status disclosure compared to other researches. It displayed 60% of the participant knew about their positive HIV status. Also those children who were on Anti-retroviral drug for more than 10 years have higher rates of knowing their status compared to those with recently starting of treatment(35).

Diverse factors are associated with HIV disclosure to children and adolescents. These are age of the child, gender, hospital admission status of the child, ART duration, fear of stigma, being alive of parents, responsibility of the child to taking his/her medications, fear of negative social consequences, shortage of knowledge about how and when to disclose and wanting support from the health care providers (33–36).

In a qualitative research done in Kenya disclosing their status occurred when their parents notice risky behavior or when opportunistic diseases occur due to poor adherence. Also self-discovery was common among the participants. They found about it from posters or browsing on the internet(37). Likewise disclosure was done between 7-15 years old in a qualitative research done in Swaziland(27).

There were various negative emotions that were exhibited by the adolescents when they were informed for the first time. (27). In another research done in South Africa, after hearing their HIV status for the first time some adolescents tried to perform suicide(26).

The participants who were first informed between ages 7 and 12 reported coping well after disclosure. But there were feelings of anger and hopelessness as they grow older and understand about the disease. Similarly those adolescents who were told after 12 years reported feelings of anger and disappointment but it was immediately after disclosure(37).

Also in a research done in Kenya there were adolescents who coped well and accepted their status at the time of disclosure(37). But in a research done in Swaziland there were neither positive nor neutral reactions to disclosure. Disclosure was done by their guardians and health care workers(27). They also added it would be good if they were told younger so that it will help them to accept their result. (37).

A qualitative research done on lived experience of adolescents with vertically transmitted HIV in South Africa showed knowing their status helps them to give care to themselves, to recognize their lives, and to live in accordance to the disease process(15).

Adolescences also should be informed of their status to promote adherence to treatment. The participants on the researches reported after disclosure they were empowered to adhere more to their medication. Because they understood the consequences of not adhering to their medication(15,37,38). Also disclosure helps to encourage safe sexual relationships. Parents also will be less depressed after disclosing to their children (15)(38).

2.3.3 Disclosure of their HIV status to others

After care givers reveal the status of HIV infected adolescents, they must struggle to tell or not to tell to their friends and their boyfriend or girlfriend.

A cross sectional study done in Cambodia among 328 adolescents between 15-17years, half of the adolescents (49.1%) had told about their HIV status to other people while the other half (50.7%) had never told to anyone. Friends and siblings are the ones mostly disclosed to(24).

In a qualitative research done in Brazil among 20 adolescents infected with HIV reported cohabitation with HIV and keeping the secret is something that is implanted in their lives. Talking about the virus brings distress, discouragement and risk of discrimination. The knowledge about the disease disclosure is limited only to families and close friends. Even with those who know about their status, they don't discuss the issues with them cause they consider it like they don't have the disease(28).

These findings are comparable to another study done in large scale in Eastern Africa, Uganda and Kenya among 582 HIV positive adolescents. Almost half of them (43.5%) had never told to anyone except health care givers. 17.9% said they had disclosed to peers and most of them received a good reaction. But few reported the reactions were not hospitable. Most Ugandans adolescents disclosed their HIV status compared to the Kenyans (39).

They also stated they mostly tell their teachers because to get academic support when being absent to school due to the illness. Some reported they don't believe their friends enough to tell them about their status. They are also afraid their friends will stop hanging with them. Those who acquired HIV vertically are afraid to disclose because most people only understand HIV comes only through sexual activity but not from their mothers too(15). Some adolescents with HIV also avoid peer relationships so as to keep their HIV status a secret(15,26).

Three qualitative studies done in South Africa among HIV positive adolescents, they have reported their HIV status is a personal secret for them. Likewise there is no need for disclosing their HIV status to other people(15,27,40).

Factors that were highly associated with disclosing to others were being older, being the bread winner of the family, self-efficacy of adolescents, more support from peers and being orphan(39). Other challenges are fear of stigma and discrimination, not telling of bad news to the loved ones(41), not to be subject to gossip, discouragement from their caregivers to disclose and fear of unacceptable behavior(15,27,40). This is similar with the study done in South Africa in which the participants don't tell their friends about their HIV status to their friends because of fear of stigma(26).

They also try to avoid topics related to HIV with their friends. Others are told by their families not to tell to anyone within their social circle(42). They are also afraid of being gossiped by others(27).

A research in South Africa explored those adolescents who told to their friends received positive reactions. These positive reactions were giving support and considering their disease as a normal illness(26). While some received care from their friends(15,42) In contrary there were adolescents who received bad reactions after disclosing to others which is discrimination, emotional suffering and stigmatization(18,48).

2.3.4 Stigmatization and Discrimination

HIV-related stigma indicates negative assessment, treatment and discrimination of persons living with HIV/AIDS. People living with HIV face different types of stigma and discrimination all over the world depending on the society and culture. This stigma may also affect quality of life of persons living with HIV/AIDS and those living with these people(43).

A phenomenological study done in Ghana stated some adolescents living with HIV have experienced stigma from their family members and people who live around them. This stigma resulted because of Ghanaian people's perception towards HIV/AIDS and also they believe this disease results as a punishment for sinful people. They also see them as they lived their life carelessly to acquire the disease(44). Also in a study done in Tanzania adolescent were discriminated by their relatives or/and their care givers. Stigmatization expressed in the parting of household utensils and similar items and by teasing and mocking about their HIV status. Also they were discriminated in schools by the teachers and their class mates(29).

In the same way HIV positive adolescents living in South Africa stated they face discrimination and stigma in their school and social circle. They stressed teachers need to teach more about the correct way of HIV's transmission and prevention methods to prevent discrimination. School programs must also be started to raise awareness about HIV and challenges with stigma(15). Similarly in Uganda adolescents living with HIV were discriminated by their teachers in a way of stopping them from school activities football clubs saying they can’t perform because of the disease(45).

In a cross sectional school based study done in Babile town, Ethiopia among adolescents showed high prevalence of discrimination and stigma. The prevalence for stigmatization of HIV positive people was 44.1%. Stigma was stated as not having fun with them, not sharing food and drink and not buying anything from them. From the 328 adolescents 57(17.3%) were unwilling to test for HIV. And 19.3% of them have misconception towards transmission and preventions methods of HIV. Their reason for stigma was fear of acquiring the disease from them (47%), due to family instruction (24.8%), for psychological reason (12.4%) and to respect other people ideas(11.7%)(46).

In a research done in Botswana about finding the behaviors associated with to prevent stigmatization and discrimination, three behaviors were listed. The first one is they adhere to their ARV drugs not to be sick so that their friends and their classmates will not know they are sick to avoid stigma and discrimination. The next behavior is keeping silent about the disease or not disclosing to anyone. The last behavior is as they encounter opportunistic diseases like influenza they seek health care treatments as soon as possible to prevent long term morbidity which is common in HIV positive patients(47).

2.3.5 Sexual and reproductive life

The adolescence age group is an important stage to teach and guide adolescence living with HIV to develop positive manners that will protect their heath and the health of other people. By providing the necessary programs about SRH for these adolescences, we can prevent distribution of the disease, decrease drug resistance, reduce the chance of reinfection and decrease the risk of other STIs in the adolescence(48).

A qualitative research done in Canada showed the adolescences are curious about sexual relationships. Their sexual life is problematical because they have HIV in their blood which is transmitted through sexual relationships. Some of the older adolescence reported they had already started sexual experience or love relationships. Even if their parents and their health care givers advise them to disclose their boy/girlfriend, they are afraid to reveal their diagnosis in fear of discontinuing of the relationship(49).

A cross sectional study done in Cambodia stated about 20% of the adolescence living with HIV/AIDS had a boy/girlfriend in the past. 2.1% of them reported they had sexual intercourse in the past one year whereas none of them used a condom during the sexual intercourse(24).

A survey and an interview were done among 740 adolescent girls and boys who are living with HIV in Uganda. 41% of the participants believed that there is nothing that blocks a person living with HIV to having sex. And 40% of the participants had been in a sexual relationship before. Of those who had sex before only 37% of them used condom to prevent HIV re-infection(50).

Another qualitative study was done South Africa among six adolescents of whom 4 girls and 2 boys to explore the lived experience of adolescents living with vertically transmitted HIV. All of the girls reported they had not been in a relationship before but they want to experience different sexual activities in the future. While two of the boys reported they were in a relationship before and had engaged in sexual activity other than penetrative sex(15).

Also researches in South Africa and Ghana revealed most of the participants are in some sort of sexual relationships. In addition the adolescents are fearful to divulge to their romantic partners which may lead to bad reactions such as separation and rejections(27,40,42,44). Most of them believed it is better to live with guilty than to disclose and lose them(44).

On the other hand in exploration done in Zambia among HIV positive adolescents stated most adolescents admit to starting sexual relationships but lack honesty in taking about their sexual behavior. They also don’t talk with other adults and parents(51). Also another study in the same country showed there were few adolescents who were active on sexual intercourse. Some broke up with them because they told them they were HIV positive. There were also who were pregnant(30).

In a survey done in Uganda When they were asked about what kind of partner they want; out of 740 adolescents 37% of the respondents prefer a person who is HIV negative. The other 29% said no preference. Generally majority of them prefer HIV negative sexual partner(50).

In the same manner, among HIV positive adolescents in Brazil and Kenya stated they have strong concern about transmitting the virus when they will be engaging in sexual activity in the future. Also they are worried about their future specifically marriage and their future relationships due to their HIV status(37,52). However they think they have to have extreme care and considerations when having sex(52).

Another study in South Africa suggests adolescence living with HIV lack enough information about SRH matters. Many of them also do not know how to use male and female condoms(48). In contrary the research done in Tanzania showed the adolescents knew about the prevention of transmission of the virus to another person and even from mother to child transmission. But most of the adolescents want to marry a person who is HIV positive as them(30).

2.3.6 Coping strategies

Coping strategies are needed for adolescents living with HIV to handle with their adverse practice such as stigmatization, drug exhaustion and declining to visit ART clinics(53).

A quantitative research done in USA examined disease- specific stressors and coping response among youths living with HIV. Among the 160 youths, 80% of them voted passive emotional regulation as a coping strategy. Blaming others and wish full thinking are listed as the least frequently used and the least and the least helpful. Problem solving was the most helpful strategy but not the most frequently used(54).

Participants in a research done in South Africa stated after knowing their HIV status, they go through accepting their new version. They had similar strategies which are family care, appointments to wellness clinics, adherence to their drugs and attending school. The support group session also helps them to interact and communicate with others(15).

A phenomenological study done in Zambia aimed to explore coping strategies of adolescents living with HIV/AIDS. The first strategy is resilience in which they are able to accept their situation and not to being bothered even if people talk about their status(53). Also in researches done in Tanzania, South Africa and Zambia; the participants stated the effective treatment given in ART clinics if they take their drugs perfectly, they can prolong their life which is a source of comfort for them. Some adolescents prefer to keep silent due to risk of rejection from their friends(15,29,53).

Other strategy is they lay on religious and spiritual interventions as a coping method. This helps them to pray to God and handle their condition(29). Also support from family, community, healthcare givers, friends, support groups and Non-governmental organizations has a great effect for coping while living with HIV. The NGOs helped them to handle their situation in different perspectives like nutritional, psychosocial and educational support(15,26,53).

2.4 Perception of adolescents living with HIV about their future plan and their need for support services

2.4.1 Support services

Different interventions were desired by adolescents living with HIV in a study done in Brazil. They stated they are satisfied with the motivations and supports they get by health care providers. But they still want more briefed information on how to prevent the transmission of the virus, review on topics related to scientific developments as well as dilemmas experienced by other adolescents in the setting of being HIV positive(28).

For the support services based on the lived experience of adolescents ADLWH in South Africa, they stated that it would be good the visits in their clinic be on the weekends and after school to prevent missing of school. They also stated it would be good if opportunities are arranged to meet other adolescents like them to share their life experience and support with each other. Also programs should be shaped for other people about HIV to prevent stigma and discrimination(26,44).

In contrast other researches in South Africa among ADLWH, they declared the support they get from their family helps them for going with their life and it is the major support they get. They also stated they need additional support from their teachers, friends and community in general (26,55). But this support is usually physical support so emotional support which is an important factor is lacking(55). They felt support when their families remind them their medication time, give them transportation fee to go to the clinic and made sure they kept their appointment(27).

Also peer support has showed a significant effect in a research done in Tanzania. It builds Positive coping towards living with HIV. It creates less HIV related distress and barriers. They also feel open in sharing their concerns and seeking help from them(29).

Another study done in Botswana among 16 adolescents and Tanzania among 12 adolescents showed the social support group provided at treatment centers helped them to become strong and create confidence(56). 93% ADLWH in Zambia from 365 adolescents also enjoy being in support groups. Also 87% stated it would be good if their adult family members attend different adult group sessions similar with them. 88% wanted a mentor who is youth and living with HIV(57).

They like and feel comfortable around the health caregivers in the clinics and encouraging one another between adolescents(57). Also in this support group information about HIV, ART, stigma and reproductive health were given. This facilitated them to accept their identity and made them realize they can live like a health person can live. Disclosure is mandatory to participate in these groups(29,37,56,57).

In general adolescents with strong family support and social supports cope better and are seen as the most important support sources by adolescents(27,56,58). And when stigmatization occurs at school they seek support from their teachers(26,56).

The participants in a research done in South Africa stated they hoped if people treated them with respect rather than hit, staring, gossiping and getting angry with them(26). Also in Uganda the adolescents expressed they are short of money to cover their school fees and they needed transport prices to go to ART clinics for fill-ups and this challenged their medication adherence, health and schooling(45).

2.4.2 Future plans

A quantitative study done among 365 ADLWH who were receiving care at the clinics in Zambia showed they want to have children in the future but they need additional information about planning for pregnancy. 93% of adolescents in the study stated they need more information on the ways for having a healthy baby. Some of the adolescents know various ways for preventing mother to child transmission but others needed more information for the future(57).

In researches done in Ghana and South Africa ADLWH stated they are afraid of death in the future. They fear they will die early due to their illness(15,44). The ADLWH in South Africa and Uganda stated even if they are afraid of death, they aspire for a better life. They considered their education as a constructive way to achieve a better future. The challenges they face in their past or in their present did not affect their view on their forthcoming life. They think of their future brightly(15,45). They also thought they can get married, got a good job and build a family in their future(15,30).

Correspondingly in another research done in South Africa almost 2/3 of the participants out of 26 adolescents felt happy about their future, they predicated they can live like a normal person by finishing their education, working and building their own family. Most of the adolescents wanted to be doctors so they could help others as they are helped by others. Also there were adolescents who have negative feelings towards the future. These feelings occurred due to being HIV infected which caused confusion towards their future(26).

2.5 Conceptual Frame Work

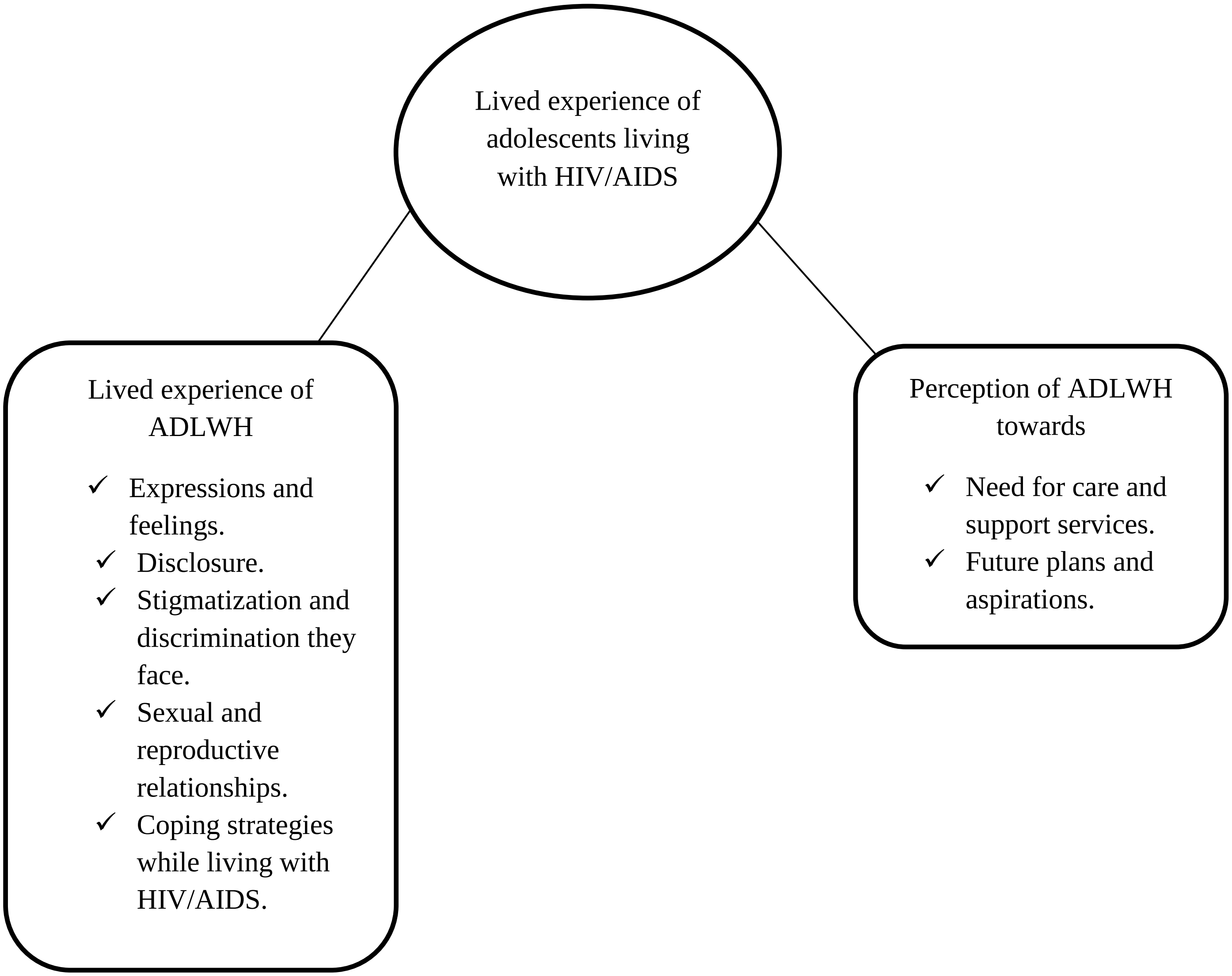

Figure 1 Conceptual framework showing the concepts that are covered by this study

3. OBJECTIVES

3.1 General objectives

- To explore the lived experience of adolescents living with HIV and receiving HIV treatment, care and support services at Tikur Anbesa specialized hospital, Addis Ababa, Ethiopia. February 8-March 8, 2021.

3.2 Specific Objectives

- To discover the lived experiences of adolescents living with HIV who are attending ART services at Tikur Anbesa specialized hospital, Addis Ababa, Ethiopia. February 8-March 8, 2021.
- To find out the perception of adolescents living with HIV about their future plan and their need for care and support services appropriate to their age at Tikur Anbesa specialized hospital, Addis Ababa, Ethiopia. February 8-March 8, 2021.

4. MATERIALS AND METHODS

4.1 Study Setting and period

This study was conducted from February 8- March 8 2021 at Tikur Anbesa specialized hospital Addis Ababa, Ethiopia.25% of the urban people in Ethiopia live in Addis Ababa which is the capital city of Ethiopia. It is also one of the rapidly developing towns in Africa(59).

In 2021 the people living with HIV in Ethiopia is estimated to be 754, 256 according to Ethiopian Public health institute prediction. In Addis Ababa in 2016 126,619 HIV positive people were living. In other ways in 2021 it is predicted 133.720 HIV positive people will be living in A.A. New infections less than 15 years old consist of 2421 people from the total of 4203 in 2016. And it is predicted to be 1,158 new cases of less than 15 years age from 3775 of new HIV infection in 2021. Adults greater than 15 who are HIV positive in A.A are estimated to be 132,562 while new infections are approximated to be 3736 in 2021(60).

Tikur Anbesa specialized hospital started work in 1972. Currently it has 200 doctors, 379 nurses and 115 other health professional who are all devoted to providing different health care services(61). The antiretroviral therapy service serves 3,500 HIV positive people in a year which composes 3,115 people greater than 15 and 385 children who are less than or equal to 15.

4.2 Study approach

This research is a qualitative study using a phenomenological approach which was used to explore the lived experience of HIV positive adolescents. Qualitative approach helps in finding out how people interpret and create sense of their practices, actions, communications and situations in the world they are living within(62).

4.3 Population and sampling technique

4.3.1 Study population

The study participants were adolescents aged 10-19 years who had acquired HIV by horizontal or vertical transmission mode. And those adolescents who were present on ART follow up during data collection period.

4.3.2 Recruitment of the study participants

TASH was purposely selected because it has a number of adolescents living with HIV who are taking ART care services at the hospital. Criterion based purposive sampling was used to recruit the study participants. The number of participants was determined by the saturation level of the information which was provided from the participants. Data saturated when the number of participants reached 15 but additional 3 was added to ensure saturation. 9 males and 9 females participated in this study which makes the total number of the participants 18 adolescents.

To reach the participants there were steps that need to be passed. First the principal investigator obtained a letter from the head of department of midwifery and nursing asking for any cooperation and to give any data that was supposed to be needed for the research. Then the principal investigator communicated with the head of the pediatric ward of TASH and the focal person of pediatrics ART. Then the principal investigator settled appropriate time and place to interview the adolescents who were willing and fulfill the inclusion criteria.

4.4 Eligibility criteria

4.4.1 Inclusion Criteria

Adolescents were participating in this research need to fulfill the following criteria:

- Adolescents from age 10-19 years and who are living with HIV.
- Adolescents who knew their HIV status and are on ART follow up for more than one year.
- Adolescents who gave assent or consent.
- Primary care givers/families who gave consent for adolescents less than 18 years old.

4.4.2 Exclusion criteria

- Adolescents who were not willing to participate in the study.
- Those who had serious health problem and admitted to the hospital.

4.5. Data collection

An in depth interview with semi-structured open ended interview guide was developed from similar research and some guides were modified in order to apply it in according to the study(15). The interview guide was developed first by English language and then it was translated to Amharic language to make it easier for interviewing. The structured interview guide included topics about biography of the participants, how their HIV status was disclosed to them, whether they disclose their status to other people, sexual and reproductive relationships, stigma and discriminations, coping strategies while living with HIV/AIDS, their future plan and support services they needed.

Before actual data collection pretest was done among 2 adolescents who fulfilled the inclusion criteria at St. Paul hospital millennium medical college which has similar set up with the study area. After pretest was done, some probing questions were added to the interview guide.

All interviews were conducted with the principal investigator in Tikur Anbesa specialized hospital. The investigator also asked the participants to forward their ideas freely and they were allowed to add anything in their lived experience of living with HIV as adolescents. All the in depth interviews were conducted in Amharic language. A room was prepared in the hospital to perform the interview with good setup and keeping their privacy.

Audio recording was done after securing permission from interviewees. Also notes were taken on their facial expression and reaction during the interview. The interview took from10-25minutes. Finally the participants were thanked for their cooperation and time for participating in the study.

4.6 Data Quality Assurance

Doing pretest helped in having a quality data. The investigator herself did all the activities from developing the interview questions, data collection, checking the data and translation were done. In addition having notes on their facial expression and silent environment helped in assuring quality of the data. Furthermore peers reviewed the transcription, translation and coding of the data.

In ensuring trust worthiness four basic criteria of qualitative study were maintained.

- Credibility: Before starting the actual data collection, the principal investigator tried to create a good communication environment with the participants. Also participants were advised to stay open and relaxed during the interview as to get the correct data. Member checking was also done which was the data collected, interpreted and summarized were checked with the participants if it is congruent with their intentions. Finally the response of each participant was checked with other participants for similarity.

- Dependability: The investigator coded an interview document two times in different times to check for the sameness of the codes for intra coder dependability.
- Transferability: this was proven by giving readers references so that the result of the finding can be applied to the same or similar situations. There was also detailed description of the research situation and methods to allow the understanding of the study to other researchers.
- Conformability: in this an audit trail was done which was recording unique topics found during the interview, giving reason for merging codes together and explaining of the meaning of the themes. Also the researcher reflected on her values and interests to see if there are any biases in the research process. And words of the participants were used in writing the finding of the research.

4.7. Data Analysis

Code book was established after few interviews were conducted. New codes that emerged during data collection were added to the code book. Data analysis was done while collecting data. Interviews was transcribed verbatim in to Amharic and then translated to English by the principal investigator. The principal investigator is fluent in Amharic and English. Transcripts were coded. Coding and analysis was done with Atlas Ti 8 software. Before themes/codes are identified the researcher fully read and reread interview transcripts, independently identified possible themes and codes and quotes and then pooled observations. An initial list of codes was then developed. Also another researcher coded some of the translated data and changes in the identified codes among the coders were corrected by conversation. Grouping related codes generated categories. Inductive Thematic analysis was used in which themes were developed which represented the whole idea of categories. Few participants were communicated again to check if the data collected and finding are congruent with their lived experience.

4.8. Standard definition of terms

Adolescence is the phase of life between childhood and adulthood, from ages 10 to 19(2).

Human Immunodeficiency Virus (HIV) is a retrovirus that causes AIDS. HIV destroys the body’s ability to fight off infection and disease, which ultimately leads to AIDS(63).

Acquired Immune Deficiency Syndrome (AIDS) is an epidemiological disease based on clinical signs and symptoms caused by HIV. AIDS is caused by HIV(63).

Antiretroviral therapy (ART) is a medical treatment which consists of a combination of one or more different class antiretroviral drugs (ARVs) to suppress a retrovirus and one of the retrovirus is the HIV which causes AIDS(63).

Living with HIV refers to a condition when antibodies against HIV have been detected on a blood test or a gingival exudates test(63).

Horizontally acquired HIV is healthcare-associated transmission by infusion of HIV contaminated blood or blood products, re-use of contaminated needles/syringes or other medical equipment, ingestion of HIV in expressed breast milk in neonatal units and sexual transmission(64).

Vertical acquired HIV is when HIV is transmitted either in utero, intrapartum or post-natally through breastfeeding(64).

4.9. Ethical consideration

The research was conducted after obtaining ethical clearance letter from department review board of nursing and midwifery, college of health sciences, A.A University. A written informed consent and assent was given to participants and their families to be filled with them. Participation was strictly voluntary. A briefing was given to all participants explaining the purpose of the research study, benefits and risks in detail.

Permission for audio recording was asked from each participant after debriefing the goal of the study. Their names are replaced by a code identification number during data collection, analysis and reporting. All the research process attended all the basic ethical principles which are respecting their autonomy, avoidance of harm, confidentiality and justice. They were also allowed to withdraw at any time if they did not want to participate during interview without any offence.

4.10 Dissemination of the result

The finding, conclusions and recommendations of the research will be presented to Addis Ababa University, College of health sciences. After correcting the comments and suggestions given; it will be distributed to Addis Ababa health bureau, Addis Ababa University, TASH and the local NGOs who are working on adolescents living with HIV to improve their quality of life. Finally the research will be taken into account to be published on peer reviewed scientific journals.

5. RESULTS

5.1 Socio-demographic Status

The participants were adolescents living with HIV who were attending ART treatment at Tikur Anbesa specialized hospital. 9 female and 9 male in general 18 participants participated in the research. The participant's age range was 12-19 years old. Six of them lived in an orphanage while twelve of them lived with their family. Their education level was from primary school to college. All of them were students except the one who was working currently in film making. Fourteen participants acquired HIV in vertical transmission while Four of them were through horizontal transmission. Table 1: Socio-demographic status of the participants for the research of lived experience of adolescents living with HIV; Addis Ababa, Ethiopia; May/2021

No	**Gender**	**Age**	**Reside with**	**Transmission way**	**Educational level**	**Occupation**
P 01	F	15	Mother	Vertical	Grade 6	Student
P 02	F	18	Grandmother	Horizontal	Diploma	Student
P 03	M	17	Orphanage	Vertical	Grade 10	Student
P 04	M	14	Orphanage	Vertical	Grade 4	Student
P 05	M	14	Orphanage	Vertical	Grade7	Student
P 06	M	17	Orphanage	Vertical	Grade11	Student
P 07	M	19	Mother	Vertical	college	Film making
P 08	F	18	Mother	Vertical	Grade 10	Student
P 09	F	18	Father	Vertical	Grade 11	Student
P 10	M	17	Mother	Vertical	Grade 11	Student
P 11	M	14	Mother	Horizontal	Grade 7	Student
P 12	M	13	Orphanage	Vertical	Grade 7	Student
P 13	M	16	Orphanage	Horizontal	Grade 7	Student
P 14	F	17	Both Parents	Vertical	Grade 6	Student
P 15	F	18	Both parents	Horizontal	Grade 11	Student
P 16	F	17	Mother	Vertical	Grade 7	Student
P 17	M	17	Aunt	Vertical	Grade 10	Student
P 18	F	12	Both parents	Vertical	Grade 6	Student

Key: P- Participant F=Female M=male

5.2 Emerged themes

After readings of the transcriptions several times and coding them; five main themes were developed with number of subcategories underneath each theme. The themes and subcategories are listed as follows.

Table 2: Themes and Categories that emerged after analyzing

Themes	Categories
Living as an adolescent with HIV	Mode of transmission of HIV
	Expressions of living with HIV
	Feelings towards HIV.
	ART drugs and health problems
Disclosure and stigmatization	Way of disclosure
	Feelings when first informed
	Appropriate way of informing
	Disclosing their status to others
	Stigmatization history
Sexual and reproductive health	past sexual relationship
	Current sexual relationships
	Perceived Spouse
Coping strategies and Supports	Coping Strategies used
	ART clinic services
	Supports they need
Future plans and Aspirations	Wants to be
	Plan towards family
	Expectations of self

5.2.1 Living as an adolescent with HIV

5.2.1.1 Mode of transmission of HIV

Out of the participants fourteen of them had acquired HIV vertically from their mother either by breast feeding or during pregnancy. Some reported they remember taking their medication from child hood while some say they remember taking some syrup. The rest of the participants acquired HIV horizontally from another person. Two of them stated it came from their father. An 18 years old girl stated

"If she (her mother) does not have the disease, I am sure there will be no one other than him (her father). He was a solider. At some time he was shut by a gun and he used to bleed a lot (Intin yil nebere). I was the one who was changing his dressings. May be that would be the reason it came to me." (P 02, 18 years old)

The other said he acquired the disease from his aunt. He was living with her since his parents has died when he was child. One participant expressed she got it when she was 8 years old from her mother's friend. And all of her family members still don't have the disease.

"It is not from my mother. I think there was a friend of my mother. She had the virus. It came because of her. I think she was giving me what she ate." (P 15, 18 years old)

Except one participant all of the participants knew correctly about the modes of transmission of HIV from person to person. One participant described she only knows it is transmitted from mother or father only.

5.2.1.2 Expressions of living with HIV

Different views were observed from the participants in expressing life with HIV. Majority of the participants explained there are different challenges and concerns while living as an adolescent with HIV. For some living with HIV is associated with taking RVI drugs for life long. They considered this a tiresome activity and also concerning. An 18 years female adolescent who acquired the virus horizontally reported like this. *"By the way it is hard to continue like this. It is hard to take medication day to day."(p15, 18 years old).* The participants also reported it is difficult to live with HIV as they have to always keep their HIV status secret. But as they take medication daily and for life long: it hard to keep it a secret always. And they need to be always secretive while living their life. A 17 years old adolescent expressed it like this

"Living with HIV is being secretive. Taking medication is a little bit freaking. You have to take it at night or early in the morning. This is difficult when you go to guest's house."(p 10, 17 years old)

Fear of death is also another expression that was reported by the participants. Few of them reported they are afraid they may die prematurely because of the disease. Even when they are sick by another disease they feel like they are going to die.

"When you are sick a little, you will be afraid of death. I feel like I am going to die. I will think I am going to die even if I have a common cold. Most of the time I used to write the things I want to do but cannot do and want someone to do it for me in the back of my diary"(P 02, 18 years old).

Also passing even little time to take medication makes them to believe they are going to die soon. A 17 years old boy expressed it like this; *"Sometimes you may pass the time to take the medicine…at that time you feel like your death day is coming near."(P 06, 17 years old)*

Some believe they have to accept what has come to keep on with their life. They stated it didn't come by their fault or they didn't create it. Therefore they just live accepting what has come to their life. Few respondents reported they live like a normal person but there are some challenges they face. These challenges occur when they meet some problems or if they are not protecting themselves that is taking their medications. 18 years old girl reported like this; *"It is difficult living with HIV. Sometimes you have to accept things that happen and to get to the better place you should live accepting things which are given to you. Living with HIV means living as a normal person. If you protect yourself you can live as a normal person."(p15, 18 years old).* Similarly other participant described living with HIV is living as normal person but you may not do and get whatever you want like others.

"Actually it is normal. You will not remember it. You can do anything like anyone else. Eating drinking you can do anything like a healthy person can do. But sometimes you feel like you are different from everyone. Even that is once up on a time (esum ke sint ande

new). For example when people think about future, you may not think about it. Your future may only be learning and living. Others future may be getting married and having children. This is not a future for me. Firstly getting married and having children is not in my mind."(p 02, 18years old)

In contrast some participants described living with HIV is not different than living as a normal person. They reported they don't consider themselves from others. They also believed they can do whatever a healthy person can do. One participant stated HIV even makes decision maker and strong to pass different challenges.

"For me it is normal there is no new impact that came to my life due to HIV. I am living doing the things I would do if I were to be normal. I would learn if I were normal I am learning now. I would exercise if I were normal I am exercising now. It didn't block me from my social life and religion too. So I am living as a normal person can live."(p 17, 17 years old)

Similarly another participant described the same thing. *"For me it doesn't mean anything living with HIV. When I was told first, I was very sad. But when I think about it after that I understood it is nothing that I can learn and think like anyone else. So I did not feel anything."(P 16, 17 years old)*

5.2.1.3 Feelings towards HIV.

More negative feelings were reported from the participants towards HIV in comparison to the positive feelings. Most of the respondents feel sad and bored when they think about their HIV status. They are angry at HIV and they consider it as enemy. They also feel they are different from other adolescents because they have HIV. Those adolescents who acquired the disease vertically also ask their God why they were created with the virus. A 13 years old male participant expressed *"I feel sad and it (HIV) makes me angry." (P 12, 13years old)*. Another participant also stated:

"I worried a lot. Even when I am in toilet I always ask my creator why he made me like this. I am angry by HIV. I also hate a lot HIV. HIV is my enemy."(P 01, 15 years old)

Adding to this some reported they also feel lonely and feel like they are the only ones who have the disease. A 16 years old participant said: *"When I first knew the first time, I felt lonely. I felt like I am the only one."(P16, years old)*. Also another participant stated like this*: "I have a headache when think about HIV, I feel sad, I always tell to myself saying I feel bad for myself differing from other children then I develop headache." (P 13, 15 years old)*

One participant considers HIV as a harmful disease which damages their life. They also believe it will influence their life in a bad way.

"It (HIV) is harmful. It is harmful when you live with it. It is bad when you are older. It is difficult to live with medication for lifelong. When I see my friends, I see their freedom and feel that is because I am taking medication. In my side I don't see the use."(P 9, 18 years old)

While some respondents stated they feel nothing towards their HIV status. Some participants who are living in an orphanage expressed they don't feel anything because their friends who are living with them are also like them. So they are similar with each other and they don't see anything new. A 14 years old male who is currently living in an orphanage expressed it like this; *"I don't feel anything because all of my friends who are with me have the virus. So I don't feel anything." (P 05, 14 years old)*

Few reported they didn't face anything until now to have bad feeling towards HIV.

"Actually I don't feel anything right now. It is different person to person. But me until now I don't feel anything. You feel like that when you face something; but I didn't face such things. That may be the reason. Even if I face since I think it may have a reason I don't feel anything." (P 08, 18 years old)

5.2.1.4 ART drugs and health problems

Out of the participants, two of them had history of being admitted in the hospital because of HIV. One participant remembered he was hospitalized when he was kid. The other participant said he stopped taking his medication when he found out his disease. So he was hospitalized since he became sick. Then after he was hospitalized and started taking the medication again.

"When I heard, I had it, I was afraid since it was said HIV kills. I heard you can only live for short time. When I heard this, I thought of stopping medication to die…I have I decided to die by not taking the medication." (P 13, 16 years old)

All of the respondents are free from any addiction except one respondent as he explained he smoke cigarettes and he couldn't stop it. He used to chew chat and drink alcohol but he stopped them now. He also has stopped taking his medication after he got out of the orphanage after he reached eighteen and he couldn't take his medication because the person he lived with does not want him to find out about his disease. He discontinued his medication for a year and he was sick so he started taking the medication again. Otherwise the other participants don't have history of stopping their medication.

5.2.2 Disclosure and stigmatization

5.2.2.1 Way of disclosure

Most of the participants were confused about the reason of taking their medication. Some of them were told in childhood so they did not felt such confusion. They always wondered and asked their parents why they are taking their medication. For some adolescents they were told they took it for heart disease. For few it was said for their current illness that may be caused by the HIV virus. A 15 years old female participant reported *"She used to tell me I have a heart disease." (P 01, 15years old)*. Similarly another participant expressed it the same way.

"I took the medicine always night and day and it never stopped. I will take it out and see it wondering what this thing is…Sometimes when my mother gets out of home I will take the medicine out and observe it. There was something about it (Yehone gir yemil neger neberew)."(p 02, 18 years old)

Most of the participants knew about their HIV status from 10-15 years old. Few of them knew at the age of 5- 10 years old. Only one participant was told at the age of 16 years old. Most of the participants heard about their HIV status from another person. For some their care givers told them when they reached the appropriate age to listen according to their care givers. For others they were told with the health workers and care givers collaboration at the hospital. Two of the participants who were living in the orphanage expressed they heard from their friends who were taking the same medication like them.

"My mother told me when we were talking in the house. When we were alone I said to her "Why do I take medications?" Then she told me I have this (crying)"(P 01, 15 years old)

Another participant also stated; *"First of all I know by my mother. When the doctor was talking I thought it was hers. I didn't know about me. When I was going to enter tea and coffee program, the doctor and my mother told me together."(P 11, 14 years old)*

Some of participants knew about their status by their own. Few said they knew about their status when the health workers were talking with their parents about the disease. Other participants expressed they saw their medication on TV displaying it was antiviral drug for HIV in AIDS's day.

"There was a celebration on AIDS day and they were displaying the image of the medication. When I took out my medication and compare it, it was similar. Then I knew I had it. I was 8 years old at the time."(P 16, 17 years old)

One participant stated she knew about it from how the people around treated her. She said there were lots of words of encouragement from others that led her to guess about her disease.

"Mine is different from others. I knew starting from my childhood. There are some children who are active from their childhood. I was like that….You know such things when repeated. And some people say 'cheer up'. So when she (her mother) told me I have the disease, I told her "I knew about it and made it easy for her." (P 08, 18 years old)

5.2.2.2 Feelings when first informed

Majority of the participants were startled and cried a lot when they heard their status for the first time. It made them worry lot and they were angry they have the disease. Different kinds of reactions were reported from the participants after being informed for the first time. Some felt lonely and thought they are the only ones who have this disease. Few hated to communicate with other people. Others thought with their teachers in their school. One participant reported she always asked GOD why he made her like this and refused to take her medication at the time she heard. She also thought of killing herself many times. She described it like the following.

"When I heard from my mother I started doubting myself even when I am in school I only think of that …I feel like the students are seeing me in bad eye. I also feel the teachers also talk saying'' she is sick and she sometimes faints" Then I worry a lot. In addition to this I am emotionally (hode basha). Then I be distant from others. I am only with my friend she likes me like me a lot"… (Crying) (P 14, 17 years old)

Another participant also expressed there were many unsuccessful trials of suicide after hearing her status for the first time; *"At one time my friend has untied a rope from me. When I was on the verge of drinking berkina after buying, someone will come (berekina rasu geziche liteta sil wey sew ydrsibingal). When they asked me what was wrong, I just told them I bought it to washes clothes. When I become a little bit grown up. My mom treated me. She told me that I can live and I will not die. That I can live until the end. After that I forgot about it." (P 02, 18 years old)*

Other participant thought he was going to die soon. He thought he even knows the day of his death is going to be. He stopped his medication for two months implying he wanted to die by not taking his medication. When he was sick, he was hospitalized and started taking his medication. He was hospitalized after and started talking his medication. He reported it like this; *"For 2 months I was very sick after that I also became very skinny after that I was taken to the hospital and I started taking the medication again. The nurses also scolded me not to discontinue again. I started the medication in the next day after that I have never stopped." (p 13, 16yeras old)*

In contrast few of the adolescents mostly those who were in the orphanage and those who were told younger took it easily. They did not felt anything at the time they were told and still don't feel anything. But one participant described he recognized it was a dangerous disease when he became older. A 17 years old adolescent said; *"I was young at that time so I did not feel anything." (P 06, 17 years old)*

5.2.2.3 Appropriate age of informing

Majority of the participants believed they were told at the right age. While few participants believed the age they were told was not right. Two participants were told at the age around 10 years and think it would be good if they were told when they are older than that age. One participant was told at the age 15 years and believed she was told late and it would be good if she were told younger than the age she was told. Although she believes being informed older has its own advantages.

"Mine is right. But it was late. I sometimes think why it was late. I was not at the age to think about it backwards. But when you are older, you will make yourself believe that it has happened once." (P 15, 18 years old)

Most of the participants believed children living with HIV should be told from 12-15 years old. They believed telling them at that age group will help them to take their medication appropriately and to keep it a secret. In addition they will also be under family guidance which will prevent them from causing problems. Also they may hurt themselves if they are told younger than that age. On the contrary some participants believed it is appropriate if they are told from 6-12 years. The advantages are first they will grow with it so they will consider living with HIV as normal. The other one is if told older they may know about the diseases and know more about life which will disturb their life. Only one participant believed children should be told around the age 20 years. A 17 years old participant expressed *"About 20 when their age reaches maturity." (P14, 17 years old)*

Other participant believed age is not the criteria to tell or not to tell them about their HIV status. She expressed it should be depending on the maturity to accept their status regardless of their age.

"It is different person to person. It is how they receive it. There is a person who is 17 or 18 but still has a child thinking. But there are some who are a kid yet think like an adult. I think it is good if they are told when they are active independence of their age. (P 08, 18 years old)

5.2.2.4 Disclosing their status to others

Majority of the participants have not ever told to another person about their HIV status. Most of them don't tell to others because of fear of stigma. They are afraid people may distance themselves and hate them. They are also afraid they will tell their secret to other person which may distribute and make their life difficult. One participant stated such kind of situation. An 18 years old adolescent said; *"But when you are living in small town, it is difficult to keep it a* *secret. The kebele's may know about it. I was working in the theatre and there was a boy who knows my status. When I was shaving with them, I think he suspected the other way. Then he told them about me."(P 08: 18years old)*. Also another adolescent who is 17 years old reported similar idea.

"It is not because I am afraid. There are some people who you believe and not. I don't tell to others because I don't believe them. For example if I tell to someone and he tells to all people, which will not be good. I don't tell to someone I don't believe." (P 16, 17 years old)

Some are warned by their family and health care givers not to tell another person. Those who live in an orphanage are warned by the nurses who are there to never tell to anyone else in fear of discrimination to the children. A 12 years old girl said *"My mother told me not to tell to anyone."P 18, 12 years old.* Few participants believe they shouldn't tell their health profile to another person. "*I shouldn't tell to anyone my health profile that's why." (P02, 18 years old)*

Those participants living in the orphanage knew their status with each other since they all have it they are not afraid to talk about it. And they are not afraid of stigmatization. A 17 years old participant who is living in the orphanage implied; *"I believe those who HIV. I think they will understand my feeling since they also have it so I tell them." P 03, 17 years old*

Likewise other participants also stated they talk freely with those who have the disease. They don't keep secrets among them. *"There are some who know from my relatives and there are also who don't know. There is friend of me who knows. She is similar to me. But she has checkup in another hospital." (P 16, 17 years old)*

Few participants had told to another person about their HIV status. Three participants have told to their friends who are negative to HIV. But they did not face stigmatization. And a good friendship was developed afterwards. An 18 years old girl implied; *"There was a girl I met at that time we kept along with each other and maintained a good relationship. We are about to reach 5 years with her." (P 08, 18 years old.* Similarly another participant said

"At the time I was told. When I went to class the next day. She knew since she grew up with me. She told me she knew about it and said I didn't want to tell you. I have not told to anyone."(P 09, 18 years old)

One participant has told to his girlfriend and she immediately broke up with him and got distant with him. He reported *"You don't know what will happen. The only one I told was her. We broke up with her. There will be stigmatization." (P 07, 19 years old)*

5.2.2.5 Stigmatization history

Majority of the participants has not faced any type of stigmatization until now. This is because most of them have never told to another person about their status. One participant reported he has not faced any discrimination because he is living around a society who is on the same status like him. A 19 years old adolescent expressed *"Since I grew up in the orphanage, I didn't face such kind of things. Everyone has it there, so it is common. Also in my village most of them have it." (P 07, 19 years old)*

Few have faced discrimination from students, Teachers and relatives. One participant said she was discriminated a friend who was learning in her class and thought of killing herself at that time. She conveyed it like this.

"At one time there was friend of mine who sat next to me in the class. When he heard about this thing, he got very distant from me and his behavior changed a lot. I felt really bad. I tried to kill myself." (P 09, 18 years old)

Similarly another participant expressed she was highly discriminated by her teacher that made her to change school. Her mother told the teacher about her status to help and understand her. But he has done the opposite.

"I am learning now by changing my school. The school I was learning before there was a teacher and my mother told him about me to help in some things. And it didn't go equally with the Koran… I don't know if he came angry from his home…I went to school without doing his homework. Then he hit and insulted me " you who have HIV" in front of the students. Then I told him I don't have such a thing. I cried from the third period until the last. Because since he is a teacher how can he says such a thing…..Then after some time some students changed on me. When I went and sit to some place, they would say get up. Then I sat

alone. Then again I told my mom and she went to the director. And he was prosecuted again. When he is prosecuted again, he made me fall his subject. So I got out of that school." (P 16, 17 years old)

5.2.3 Sexual and reproductive health

5.2.3.1 past sexual relationship

Most of the participants were not in sexual relationships before. But all of them have never had sexual intercourse. Three participants reported they were in relationship before. But they already broke up now. One participant stated her father stopped her when he heard about her relationship due to her disease. Even if her boyfriend had the disease, she implied he told her she shouldn't be with anyone and only should be concerned about her education. She said *"I had before but due to disease my father stopped me saying you should not be with anyone…my father told me you should not be with him even if something happens no one will help you… I said okay and started following my education." (P 14, 17 years old)*

Two participants broke up with their lovers because the participants wanted to have sexual intercourse with them. One participant said he told his girlfriend but she broke up with him. A 19 years old male participant reported;

"We were in the tenth grade. She (his girlfriend) had an interest for sex….. Then I told her I have it (HIV). I told her we can do it by condom, afterwards she moved further away from me. I also left that school because of that." (P 07, 19 years old)

Similarly another participant broke up with her boyfriend because he wanted sexual intercourse. She couldn't go on with it because she has HIV. But she did not disclose her status to her boyfriend. She avoided the topic by stating she has no interest for sexual intercourse. The disease resulted in breaking up her love relationship.

"We broke up before covid comes. At some time we were talking and a topic about children came up. His sister's daughter delivered a baby at that time. He asked me when is going to happen ours? I told him I don't like such a thing. And then he asked me again and again. I told him I can't do it. I told him "if you want to do it, you can go and do it with another girl". Then he got crazy. I told him I don't like such a thing."(P 08, 18 years old)

Both of the participants reported they could have done sexual intercourse without telling their spouse but they didn't want to hurt and infect their lovers with HIV. An 18 years old female participant said *"If I were to continue with that, I could have done it. But because I like him I preferred making him sad and go away." (P 08, 18 years old)*

5.2.3.2 Current sexual relationships

Majority of the participants are not in sexual relationship currently. Only three of the participants have lovers currently. Two of them are male and they are 17 years old. Their girlfriend's age is also 16. Their girlfriends are negative of HIV and they also don't know about their boyfriend's HIV status. But they have not started any sexual intercourse until now. The participant's also don't have intentions of telling their girlfriends their HIV status in recent time. They also worry what their lovers may do if they know about their HIV status.

"I am concerned because I may not continue with my girlfriend if I tell her." (P 06, 17 years old)

Similarly another participant said; *"If I am able to stay with my girlfriend….What she will do after she knows…" (P 3, 17 years old)*

One participant expressed she is in relationship with a boy who is 18 years old, the same age as hers. He is infected with HIV and they both know about their HIV status with each other. They also understand and help with each other.

"Now since I have a boyfriend, I don't have any concerns. But before I always think how I am going to tell him when I have a boyfriend. If he is from outside, how I will tell him made me worry. But now I do not have any concerns." (P 09, 18 years old)

5.2.3.3 Perceived Spouse

All of the participants believed they need to tell their lovers first about their HIV status before engaging in any sexual intercourse. But they reported they should tell after starting relationship and depending on what kind of mind set she/ he has.

"I will see first what kind of psychology she has. I will choose for what kind of person I need to tell. If she tells to the person she meets even if it is nothing for me I shouldn't expose my health profile." (P 17, 17 years old)

Some of the participants reported they want HIV positive spouse to marry in the future. This will help them in understanding with each other. An 18 years old female participant said *"Someone who has it like me because he understands my illness." (P 09, 18 years old.* They also stated it will help them to strengthen their relationship. *"But if she has it, she will be close to me knowing that I have the virus. Also for me I will be close to her thinking she has it." (P 03, 17 years old).* They are also afraid if they marry HIV negative person, they may transfer the virus to them. A 14 years old adolescent said; *"I want the one who has it so that I will not transmit it." (P 04, 14 years old)*.

Three participants reported they want a spouse who is HIV negative.

"It is better if he (her future husband) does not have HIV." (P 01, 15 years old)

Other participants reported they don't care about their spouse's HIV status. If the other person is comfortable with it while knowing their status, they can go on with HIV negative person. Also few participants expressed if the transmission of HIV can be prevented they preferred marrying HIV negative partner.

"I don't care for me as she is comfortable but I prefer if she is positive more because I will not infect a new person if it is not anything for her for me it is not a problem." (P 17, 17 years old)

Similarly a 17 years old participant expressed like this *"If it can't transmit it to her, I prefer negative." (P 10, 17 years old).*

Some participants reported they don't even want to start any type of sexual relationships because of their disease. They don't think about marriage because they may infect another person with the disease. A 16 years old male participant reported *"I gave up; I will not even come near to women." (P 13, 16 years old)*

One participant reported she is worried she may not marry the person she wants because of her HIV status. She said *"I think it will disturb my married life. My insides tell me I can't be with the person I want." (P 08, 18 years old)*

5.2.4 Coping strategies and Supports

5.2.4.1 Coping strategies

Different kinds of coping strategies were adopted by the participants while living with HIV. The first one is keeping their HIV status a secret which most of them used. Almost all of them have not told to another person about their HIV status. They reported they don't tell about their HIV to other people about their HIV status which will help them to be considered as a health person in the eyes of the others. Two 18 years old adolescent reported it like this

"No one knows other than my family. It is closed in the family." (P 15, 18 years old)

"It is my secret until now." (P 02, 18 years old)

For few the other coping strategy is even if other people hear about their HIV status they don't care. They stated they don't feel anything. "*There are some people who know about it. I don't care if someone knows I am doing more than some normal people can do. Frist it is not something that I brought, second I didn't lose anything because of it came." (P 17, 17 years old)*. Similarly another participant said; *"I don't like it. Because their understanding is different from person to person. They may talk about you in your back. Actually even if they talk, I don't care." (P0 08, 18 years old)*

Some participants reported by taking their medication they can be free of an illness which helps them to be stress free. They believe if they take their medication correctly they can live as a normal person which is a source of comfort to them a lot. This also helps them to consider the disease easily.

Additionally some participants reported family support is one of the coping strategies which help them while living with HIV/AIDS. Family support helped them to continue with their life and helped them not to give up in their life. An 18 years old participant stated; *"When I become a little bit grown up. My mom treated me. She told me that I can live and I will not die. That I can live until the end. After that I forgot about it." (P 02, 18 years old)*

"If we talk about the virus, the necessary point is with the family. If family doesn't have good understanding for me, you will not have too. My families are very essential for me. So I want to thank them." (P 15, 18 years old)

One participant reported she believes she will be free from this disease by being healed. She said if I become strong and prayed maybe GOD can heal me one day. He said *"I always think I will be healed. Even if I am swallowing the drug I will be healed. I think one day I will be a human." (P 01, 15 years old)*

Similarly another participant stated that he hopes he will be healed one day by taking his medication properly and by being clean. He has false assumption that HIV can be cured by taking medication correctly.

"I think I can be free from this disease by following up my check-ups, by taking my medication properly and by keeping my hygiene." (P04, 14 years old)

5.2.4.2 ART clinic services

Most of the participants are satisfied with the services they get at the ART clinic. They reported that they treated them like they are their own child. They described they get priories in the services they utilize. They are advised to take their medication properly. Some even don't want to go to adult ART service because they like pediatrics ART clinic. A participant who is 18 years old said *"It is good in them (the health workers). There are not any bad sides. They share with you what they have seen. They guide you about things." (P 15, 18 years old)*

But there are some services they wanted them be improved. One participant reported it is hard to talk to them when the health workers are new at the clinic. Another participant described there is a language barrier between her and the health care givers. They also reported there is long line in pharmacy dispensary. There are also difficulties on the laboratory service. The results take time to be out and they may even go missing.

"We give investigations that are CD4 and viral load. After we gave, when we come here after many days they will say it is missing. And then we will give again. Since we are many, it would be good if we were to have our only laboratory."(P 09, 18 years old)

Few also reported there are some health care givers who are negligent about them. One participant described that it is problem when they are writing sick leaves. She reported they state their disease in their sick leave paper which discloses their status to others.

"Most of them they are students. Even when they are writing sick leave, they wrote you the name of the disease. Once up on a time some doctor wrote it saying HIV. And I asked him "what is wrong?" He said "You don't want it to be known?" (P 08, 18 years old)

Another participant added it would be good if more counseling is given when they come there to get their medication. She said; *"Most of the time people like me will give up at some point. I know it because I was there. You will be weak in your belief. It would be good if they give us advice about this." (P 02, 18 years old)*

There is a tea and coffee program they participate with each other. Most of the participants participate in the program and they like the services they get there. One participant stated she does not want to participate in tea and coffee program because of fear of being exposed and be known by others as HIV infected person. Most of them reported when they first started they realized they are not the only ones who are HIV victims. It made them realize many people have the disease more over even their equal ages.

"Before I entered tea and coffee program, I was very shy girl. That may be because I was kid too. When I entered I met a lot of kids whom I know. And I said to myself "p 09 you are not the only one". (P 08, 18 years old)

Similarly 17 years old adolescent stated; *"They told us we are not the only ones and there are many like us." (P 10, 17 years old)*

The tea and coffee program helps them to communicate with each other. They also get education about sexual relationships, stigmatization, future plan, ART drugs relationship with the disease and about the disease itself.

"At some point we talked about what we discussed before…about how to be intimate with your girlfriend (ahun silanesanew girlfeind aqrareb minamin tnseto nebere). How a person who has the disease communicate with others. How he/she is stigmatized. We talk about these things." (P 03, 17 years old)

"…when I entered tea and coffee program I was more stable. In tea and coffee program, there was different kind of educations." (P 10, 17 years old)

They also meet different friends and don’t feel they are not alone.

“But after I started tea and coffee program, that feeling disappeared. When I first heard, I thought I was the only one in the world. But in the discussion I recognized I am not the only one and there may also be some who doesn’t even know their status while they have it. So I did not feel anything.” (P 16, 17 years old)

Few explained it helps them to get a friend to talk with. It also helps them to find spouse since all of the participants that participate HIV positive and can have spouse who have the same disease with them.

“I am sure tea and coffee program is created so that we can create sexual relationships with each other.” (P 08, 18 years old)

Some participants explained it will be better if some services are added. One participant explained there is age difference between the participants. It would be good if they have similar age in the group. A 14 years old male adolescent described it like this; *I am not participating with my equals. Because I am participating with those who are older than me now. If they are equal to my age I would be happy. (P 11, 14 years old)”*

Another participant recommended if there is more entertainment that will be added in the tea and coffee program.

“I think before I entered there was entertainment there is sometimes was going outside of the city. It would be better if it is not only talk about but some entertaining too.” (P 17, 17 years old)

5.2.4.3 Supports they need

Most of the participants reported there is lack of knowledge and understanding among the society. They stated there is also discrimination both in educated and uneducated person. An 18 years old girl said;

“Not only the uneducated but the educated ones also don’t know anything. I am a teacher. There was a psychology expert. But he talks with fear. He doesn’t have freedom. For example let’s say he doesn’t know me. If I were to fall, he would pick me because he doesn’t know about me. But if they were to fall, he wouldn’t pick them. There is this thing,

because they know them they will discriminate them. I think the uneducated and the educated ones needs to change well." (P 08, 18 years old)

The participants also stated it would be better if people don't discriminate HIV positive people.

> *"From the society there are some people who reveal themselves to media. From what we heard from our neighbors, they will say this girl and things like that.(Wiy yichi lij minamin yilalu). It would be good if things like this are stopped because no one gets it because he/she wants it. It came may be because of his/her mother and father's mistake." (P 02, 18 years old)*

One participant said there is also a problem when teachers teach in schools. He thought they make the disease very frightening and the student became afraid of a person with the disease. They consider the person as another creature.

> *"It would be good if we don't live in fear. I think there is a freaking part when teachers are giving education." (P 07, 19 years old)*

More education also needs to be given for the society about HIV to improve their understanding. A participant who is 18 years old said; *"The society doesn't have thoughtfulness. Even if they know, they act like they don't know anything. Firstly at this time, everyone knows. Everyone learns about this problem. But the society acts it doesn't know. Still there are many who made themselves distant when they hear about such things. It is needed more education about this." (P 09, 18 years old)*

Also there needs to be more education given for students so that they don't stigmatize people with the disease. Other supports they need from the society are psychological support. They hope a person next to them who would support them. A 14 years old boy said; *"And those who are not infected should treat the infected ones as a brother and mother and be together with them." (P 04, 14 years old)*

> *"It is good if the society takes the education well. The person who had the disease needs many things. It would be good if one person come and say cheer up." (P 16, 17 years old)*

The participants also stated the society need to take more precautions on HIV. People are forgetting about the disease. Also those who heard about other's HIV status they need to keep it a secret for them. An adolescent whose age is 14 also described it like this; *"For the society…. So that they will be exposed to HIV they need to protect themselves during sexual intercourse. And they need to stop the transmission of HIV from person to person." (P 05, 14 years old)*

Some described they are getting a good support from the government. But they need some additional supports they want to get. These are financial support, increase entry of medications, a more advanced medication and more work opportunities for those infected.

"Sometimes there is shortage of medication. I have taken 15 days medication n because I couldn't take a month. It would good if there is good supply of medication." (P 16, 17 years old)

Likewise, 18 years old participant said

"It is good if the government works more in us. Everyone in its job… Even the scientists... We will not expect the cure directly. But it would be better if there is improvement in the present medication." (P 9, 18 years old)

Few participants hoped that they will be healed one day because a cure for HIV will be gotten one day. A 16 years old participant stated; *"And also I have a hope that a cure for HIV will be gotten in the future." (P 10, 16 years old)*

5.2.5 Future plans and Aspirations

5.2.5.1 Wants to be

Most of the participants have different aspirations toward what they want to be. Most of the participants want to be a doctor in the future because they want to help people in that field. Others wants to be painters, artists, astronomers, film makers, defense force(solider), pilots, accountant, engineer and study computer science. *"It is my dream. I want to help people by becoming a doctor." (P 15, 15 years old.* Likewise another participant said *"I want to be a lawyer."(P 09,18 years old)*

One participant said he wanted to be entrepreneur because there are many who are job seekers but he want to be a job creator to create work opportunities for others. He said;

"I am going to be a lot of things there are some that I started now. When I was a kid I wanted to be a doctor. But now days I am interested on computer I took online course in summer and I am a software developer now in the future I wanted to be entrepreneur I am moving on it by planning." (P 17, 17 years old)

5.2.5.2 Plan towards family

Majority of the participants want to get married and have children in the future. For some it is a must thing to do. They also think of building their own family. An 18 years old female participant said; *"I think my thoughts will be a success. I will have a job. And a family with children." (P 09, 18 years old).* Similarly a 17 years old participant having her own family is a must. She said *"Of course, is there anyone who doesn't want (building a family)?!" (P 16, 17 years old).*

One participant reported she is afraid she may not get a husband she wants someone who has the disease like her. So she is worried about her future marriage.

"I can only marry someone like me, right? But I hang out mostly from the outside. They can't fulfill my criteria. (P 08, 18 years old)"

Another participant explained he will only marry if he is healed of his disease. He has false assumption that he can be healed if he takes his medication correctly. He said *"It is just as I told you. If she has the virus I will tell her not to transmit to the child. If I am cured from the disease, I would be happy. Because I will have a lot of things to do." (P04, 14 years old)*

For some getting married and having children is optional. It depends on the situation that will happen at that time. Depending on the situation they will be they may or may not get married. A 16 years old male adolescent said; *"I haven't thought about it. Maybe in the future." (P 10, 16 years old)*

Similarly 19 years old male participant said; *"I don't know. Now what I want is making my mother free from poverty. I don't have a thought of building a family." (P 7, 19 years old)*

Others stated they don't even want getting married and having children in the future because of their disease.

5.2.5.3 Self expectation

All of the participants were asked how they see themselves after 10 years. Most of them view themselves in a bright future. They reported they would have a job at some place. They may have their own family and children in the future. They will also support their family.

"After 10 years I will finish my education and I will have a work. And my mother has no job and house. I want to give her a job if she can. I want to achieve this." (P 10, 15 years old)

One participant he would be a CEO of a company that is the one he would create after 10 years. He hopes he would have many workers under him at that time. A 17 years old participant said; *"I don't know I would be a CEO of a company. I will be in some place." (P 17, 17 years old)*

In the opposite a participant expressed she doesn't expect herself after 10 years. She reported she doesn't plan for more than two years. Because she may die because of her disease. She said;

"After 10 years… I don't plan those much long plans. I don't like planning for longer time….I think I will die at same time. And I will never be healed." (P 02, 18 years old)

6. DISCUSSION

The research aimed to explore the lived experience of adolescents who are living with HIV/AIDS at Tikur Anbesa specialized hospital, Addis Ababa. Participants on this study described their life experiences about expressions and feelings towards HIV, disclosure and stigmatization, sexual and reproductive life, coping strategies, supports they need, their future aspirations and plans.

In this study both adolescents who acquired HIV through horizontally and vertically were included. The participants who acquired the virus horizontally acquired it from their father and nearby relatives. This is similar with the research done in Ghana in which both adolescents who acquired HIV horizontally and vertically participated. But most of the participants acquired the virus horizontally which is in different from this study (44). However in this study majority of the participants acquired the virus vertically.

The participants in this study expressed living with HIV has several bad influences. Taking medications everyday was considered as a tiresome activity. They also expressed living as an adolescent with HIV is being secretive and not sharing their secrets with other people. This is similar to the research done in Brazil in which their HIV status is their secret which they don’t share with others other than family(28).

Participants described different kinds of negative feeling towards HIV. These feeling are being sad, bored, feeling different from others and loneliness. Also they consider the disease as their enemy and something that will affect their life negatively. These findings are consistent with the results found in Brazil, South Africa, Tanzania and Zimbabwe in which negative feelings get the superiority compared to the positive feelings(26–29).This may be because they have similar setup to the study area.

Fear of death is another feeling they exhibit because of the disease. This is similar to the researches done in Swaziland and South Africa in which they feared death when they were first told and through time they incorporated HIV into their life(15,27,42). There are also some who reported they can live like a normal person can live. Although they have to take care of them to live like that. Also the participants believe they are capable of doing what a health person can do. There is nothing that blocks them from doing what they want. This is similar to the researches done in Brazil and South Africa(28,29).

There are also participants who didn’t feel anything towards HIV. They take it normal as something that lives with them but not more than anything Which is similar to a research done in Tanzania(29). There are some participants who stopped their medication due to various reasons. To deliberately die without taking the medication is one of the reasons. This finding is consistent with the research done in Brazil additionally not to take in front of people so they will not find out about their disease another reason (28).

After disclosure confusion that was caused by the reason for taking their medication was erased from the participant’s life. Disclosure helped them to better understand their disease and resulted in increased adherence. The disclosure age ranged from 10- 15 years old. They were informed for the first time by their parents, relatives, health care providers and friends. Others found about it from advertisement about the ARV drugs and how others treated them by themselves. This is similar finding to the research done in Kenya in which some participants find out about their status by themselves(37). There are also participants who knew when their parents talked with the health workers about the disease. This finding is similar with the researches done in South Africa and Swaziland(15,27).

The reactions observed from the participants when they first heard about their status were being startled, crying, worry, angry and suicidal feelings. Additionally they also decreased communication with others, fought with their teachers and fear of death was developed which is similar to a study done in Swaziland(27). In contrary there were also some who took it easily and did not feel anything. This is different from the research done in Swaziland which reported there were neither positive nor neutral reactions to disclosure(27). This may be because of sample size difference to notice such reactions.

Most of the participants believed they were told at the right time. Those participants who said it was the right age they were told from 10-15 years old. Others reported they were told younger and older than the age they were told. Participants recommended the right age to tell children about their HIV status is inform 12-15 years old. Telling adolescents at this age helps them to their health properly. Others recommended it should be between 6-12 years old because it will help them to consider the disease as normal as they will grow with it.

The participants don't tell others about their HIV status due to different reactions from people. Discrimination is the main reason they are not disclosing to others. There are different reactions gotten from people which are hate, distancing themselves from them and exposing them to other people. This outcomes are similar to the researches done in South Africa and Swaziland(15,26,27,42).This may be because the society is similar with the research area. Other reasons are fear of unacceptable behavior from people such as gossip and distress. Also some are warned by their families or Health care givers not to tell to anyone. This finding is similar to the studies done in South Africa and Swaziland(15,27,40).Some disclose to teachers to help and support them similar to a research done in South Africa(15). But they don't hide their status from those who have the disease since understanding with each other will be there.

Those who have told to others face good and bad feedbacks. A friendship becomes stronger after a feedback wherein some received care and they considered their disease as normal. Although breaking up the relationship and distancing were the bad reactions they experienced. This result concedes with the researches done in South Africa(15,40).

Though most of the participants didn't face stigmatization, there are few who have been discriminated that led them even to the thought of suicidal and changing schools. Some discrimination occurred from family members and those who live around them. This is similar to the researches done in Ghana and Tanzania. Parting household utensils and teaching them were the way they are discriminated(29,44). Some teachers also discriminated them and made them again being discriminated by the students. Their family told the teachers to support and help them but the information resulted in further stigmatization. This is similar to the researches done in South Africa and Uganda (15,45).

Coincidently there were no participants who had sexual intercourse until now which is different from the research done in Canada and Swaziland (27,49). Few participants who were in sexual relationship broke up with their lovers because the other parties wanted to have sexual intercourse. Their boy/girlfriends broke up with them knowing their status and even without knowing their status which similar finding to the researches done in Tanzania(30).

Currently there are participants who are in sexual relationships with the same HIV status. Also there are some in relationship with negative lovers but their spouses don’t know about their HIV status. And they worry what they will do if they find out about their HIV status and afraid to disclose their status to their lovers this consistent to the research done in Canada, Ghana, South Africa and Swaziland(27,42,44,49). Almost all have good knowledge about HIV transmission and prevention methods similar to research done in Tanzania(30).

Most of the participants perceived a positive spouse for the future so that to understand and help with each other. Also not transmitting the virus to others is their reason. They also believed they have to tell their future spouse about their HIV status before marriage. There are also those who don’t give care to their spouse’s HIV status. If the other person doesn’t care it is okay to go on with it. Few of the participants preferred HIV negative spouse for the future. Similar to studies done in Uganda and Tanzania where majority preferred HIV positive spouse(30,50). The participants are also worried about their future sexual life as the disease is transmitted by sexual intercourse. Likewise researches done in Brazil, Canada and Kenya revealed the same thing(37,49,52).

Different types of coping strategies were employed by the participants while living with HIV. These are being secretive of their status, staying health by taking their medication properly, assumptions that they can be cured in the future different supports they get from their families, communities and government helps them to cope up with their life. This is similar to the research done in Zambia, Tanzania and South Africa(15,29,53). Also resilience is another strategy even if someone hears and discriminate them they don’t give care. Similar to a research done in Zambia(53). Also believing in religion that is they believe may be God can cure them from their disease one day similar to a research done in Tanzania(29).

The services they get in Art clinics are very satisfactory as reported by the participants. They are treated as a family. Similar to a research done in Zambia and Brazil (52,57). But language barrier, long lines in laboratory and pharmacy services and negligent health workers are those that they needed them to be improved. Also they stated some health care givers write their diagnosis in their sick leave papers which might disclose their HIV status to others.

Also the support group which is the tea and coffee program helps them a lot in their life. They reported it has magnificence effect to motivate and support them. It helped them in different ways. It helped them to eliminate the feeling that is they are the only ones with the disease. They also get knowledge in sexual relationship, stigmatization, ART medication and they talk about their future plan. It also helps them to meet friends and even future spouse. Similar to a research done in Swaziland and South Africa(15,27).

The participants reported there is stigmatization towards HIV positive people in the society and it needs more education. More education should be given for students not to discriminate class mates. Family and psychological support are the supports that are helped them to go on their life. Similarly researches done in but they need additional psychological support from their family. Similar to research done in South Africa(26,55). They are satisfied with the supports they get from the government but they added and hoped if an advanced medication or a cure for HIV will be developed as the science is progressing further. And they would like it if they are helped financially too. Similar to a research done Uganda(45).

They have bright aspiration towards the future. Most of the participants wanted to be doctors to help as they are helped which is consistent with the research done in South Africa(26). Others want to be painters, artists, astronomers, film makers, defense force (solider), pilots, accountant, engineers and study computer science. There are also few who don’t see themselves in the future. They are afraid they may die early because of their disease similar finding to a research done in South Africa and Ghana(15,44). Also most participants wanted to build a family and have children in the future. And don’t want to get married in the future Also some don’t want to build their own family because their disease might disrupt their sexual life comparable to a research done in South Africa(26).

Most view themselves in a better place after 10 years. They don’t consider the disease will affect their future life. They view themselves as a healthy person can view him/herself in the future. They view they may be working in some place and having their own family although this may not apply to all. This result is consistent with the researches done in South Africa and Zambia and Uganda (15,45,57).

7. STRENGTH AND LIMITATIONS OF THE STUDY

Strength of the study

As to my knowledge, this is the first research done about the lived experience of adolescents living with HIV in Ethiopia. Also reaching such population and exploring their lived experience through in-depth interview are the strengths of the study.

Limitations of the study

Majority of the participants were obtained from adolescent who acquired HIV vertically which may be different in their thought, activities and attitudes to those who acquired HIV horizontally. Adolescent who acquired the virus in their adolescent age through sexual intercourse couldn't be gotten as there is limitation of time to wait them to come for their ART follow up which hindered to explore about their lived experience. Also not having focus group discussion is one of the limitations.

This study is also only dependent on the adolescents view. It could be good if families, health care providers and other views are studied. Finally, the participants may have omitted some information about their lived experience while living as an adolescent with HIV to avoid social bias.

8. CONCLUSION AND RECOMMENDATIONS

Conclusion

This research explored the lived experience of adolescent who are seropositive for HIV who acquired it horizontally and vertically. Five themes were developed which are used to report the lived experience of participants. Most of the participants have negative feeling towards HIV. First disclosure in HIV resulted in being sad, cried, angry and hated communicating with others. After disclosure benefits were gotten that helped to increase adherence of drug and they understood about their disease. Most of the participants don’t disclosing to others in fear of discrimination and those who disclosed received both good and bad feedbacks. Most have never been discriminated because they have never told to others other than family. Relatives, teachers and friends are the people who discriminated them.

In few participants HIV had affected their sexual life which resulted in breaking up their relationship. Majority of the respondents wanted the seropositive HIV spouse in the future. The coping strategies used were being secretive, resilience, taking medication appropriately, family support and religion. They are happy with the service they get at ART clinics and youth club though there are some who they wanted them to be improved. Majority of participants have bright future about their life and some wants to have their own family in the future.

Recommendations

Based on the finding various interventions at individual, community and organization level are recommended to responsible bodies to address the health requirement of adolescents living with HIV.

- ➢ For ministry of education
    - ✓ Schools and teachers should have to include lessons about HIV/AIDS in the curriculum specifically to teach students about HIV stigmatization and discrimination. Also to help and counsel those adolescents who are living with HIV.
- ➢ For Addis Ababa health bureau, NGO and others institution working on HIV/AIDS.
    - ✓ To form youth clubs that involve adolescents who are living with HIV as it has numerous advantages to improve their life in different hospitals and health centers which don’t have until now.
    - ✓ To cultivate the awareness of the society around HIV/AIDS to eliminate stigmatization issues and towards the adolescents
- ➢ For Hospitals and health centers.
    - ✓ It is recommended to add counseling to their services given and to improve the services in laboratory and dispensary service.
- ➢ For families of adolescent
    - ✓ To support their children in social and sexual relation issues.
- ➢ For researcher
    - ✓ To further study which include their guardians, health care providers and stakeholder to address their health requirements
    - ✓ To study the lived experience of adolescents who acquired HIV in their adolescent age horizontally

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APPENDIX

Appendix A; English version of Study participants (Adolescent's) information sheet and consent/assent form

Title: Lived Experiences of adolescents living with HIV/AIDS at Tikur Anbesa specialized hospital, Addis Ababa, Ethiopia.

Principal investigator: Mihret Fikreyesus Yami

Name of the institution: Department of nursing and midwifery, College of Health Sciences, Addis Ababa University.

Hello! I am Mihret Fikreyesus masters of pediatrics and child health nursing graduating student from Addis Ababa University and currently I am doing a research about the lived experience of adolescents living with HIV/AIDS. The research discusses about how HIV status disclosure was, how disclosure to others happen, if there are stigmas and discriminations, about sexual and reproductive life, about coping strategies while living with HIV, their future plan and support services they need.

Purpose of the study: This study's goal is to explore the lived experience of adolescents living with HIV/AIDS, so the result of the research will be useful in attaining improved health care services, to improve the quality of the life of adolescents living with HIV and to further control HIV transmission.

Study procedure: The research includes adolescents 10-19 years. Willing participants in this study will be interviewed on a few questions regarding their life experience of living with HIV. It may take 45-60 minutes. Memos may be taken during the interview. Also we will use a small recorder if you approved and short speeches from the interview will be used in reporting the final results of the research. As well you will be requested to sign on the consent form for your voluntariness. Results of this study will be shared over presentation, but your name will not be mentioned with the report.

Possible risks/ discomforts: There is not any harm associated with this study. But you may feel uncomfortable psychologically in addressing some of the questions relating to your lived experience of living with HIV. In case you experience any severe distress please let me know and I will discontinue the interview and will be continued if you feel like.

Possible benefits: At the moment, this study will not be of direct benefit to you, but I expect that findings from this study may help the policy makers to make verdicts in designing appropriate programs, strategies and policies that will be advantageous indirectly to you and other adolescents living with HIV in the society.

Data confidentiality: All the data's from this interview will be handled so as to protect confidentiality. No one's name will be mentioned and the information will also be coded. I guarantee you that all the information provided about you such as your name and audio record of the interview will be protected from public and your personal identity will not be mentioned in any report of this study.

The interview will be audio recorded only to facilitate the interviewer's job. The audio recording of your interview will be written out but your name and other identifying information will not be written. Your name will be assigned a code number and this number will be used in all reports. All details of your information will be stored and secured in a pass ward protected files in the researchers personal computer. Name or physical address of participants will not be used during report sharing and communication of findings.

Voluntary participation and right to leave the research: Participation to this study is voluntary and you have the right to decide whether to participate or not. You also have the right not to participate in this study or withdraw from the study if you wish without any worry.

Payment: there is no payment for study participants since; the interview is to be conducted while the participants are attending care in the hospital.

Study participants' (Adolescents') Informed consent/assent form

The above information sheet describing the study purpose and procedure, benefits and risks, confidentiality issues, voluntary participation and rights to withdraw for the research title "lived experience of adolescents living with HIV/AIDS at Tikur Anbesa specialized hospital" has been read and explained to me. I have been given an opportunity to ask any question for more explanation about the research. I agree to participate as a volunteer. 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

Name and signature of volunteer _______________

Date __________________

I certify that purpose of the study, potential benefits and possible risks associated with participating in this study was explained to the above individual.

________________________ ____

Date Name and signature of researcher

Appendix B; Amharic version of study information sheet and informed consent form

ለጥናት ተካፋዮች መረጃ

ርዕስ-በኤች.አይ.ቪ / ኤድስ የተያዙ በታዳጊ ዕድሜላይ የሚገኙ ወጣቶች በጥቁር አንበሳ ሆስፒታል አዲስ አበባ ፣ ኢትዮጵያ

ዋና መርማሪ-ምህረት ፍቅሬየሱስ ያሚ

የተቋሙስም የነርሲንግ እና የሚድዋይፈሪ ትምህርት ክፍል፣ የጤና ሳይንስ ኮሌጅ፣ አዲስ አበባ ዩኒቨርሲቲ፡፡

ጤና ይስጥልኝ! እኔ የአዲስ አበባ ዩኒቨርስቲ የህፃናት ህክምና ነርስ ተመራቂ ተማሪ ምህረት ፍቅሬየሱስ ነኝ እናምበአሁኑ ወቅት ከኤች አይ ቪ / ኤድስ ጋራ አብረውበሚኖሩ ታዳጊዎች ላይ የኖሩትን የህይወት ልምድ በተመለከተ ጥናት እያደረግሁ ነው፡፡ ጥናቱ የኤች.አይ.ቪ ውጤት እንዴት እንደተነገራቸው ፣ ለሌሎች እንዴት እንደሚናገሩ ፣ መገለሎች እና አድሎዎች ካሉ ፣ ስለ ወሲባዊ እና ተዋልዶ ሕይወት ፣ ከኤች አይ ቪ ጋር አብረው በሚኖሩበት ጊዜ ስለ ስልቶች መቋቋም ፣ ስለወደፊት እቅዳቸው እና ስለሚያስፈልጋቸው የድጋፍ አገልግሎቶች ላይ ትኩረት ያደርጋል፡፡

የጥናቱ ዓላማ -ይህ ጥናት ዓላማውበኤች አይ ቪ / ኤድስ የተያዙ በታዳጊ ዕድሜላይ የሚገኙ ወጣቶች ያላቸውን የኑሮ ተሞክሮ ለመዳሰስ ነውስለሆነም የተሻሻሉ የጤና እንክብካቤ አገልግሎቶችን ለማግኘት ጠቃሚይሆናል፡፡ በተጨማሪ ከኤች አይ ቪ ጋር አብረውየሚኖሩ በታዳጊ ዕድሜ ላይ የሚገኙ ወጣቶች የሕይወታቸውን ጥራት ያሻሽላል እና የኤች.አይ.ቪ ስርጭትን የበለጠለመቆጣጠር ይረዳል፡፡

የጥናት ሂደት፡ -ጥናቱ ከ 10 እስከ 19 ዓመት ዕድሜያላቸውን ታዳጊዎች ያጠቃልላል፡፡ ከኤች አይ ቪ ጋር የመኖር የሕይወት ልምዳቸውን በተመለከተ በዚህ ጥናት ውስጥ ፈቃደኛ ተሳታፊዎች በጥቂት ጥያቄዎች ላይ ቃለ መጠይቅ ይደረግላቸዋል ፡፡ ቃለ መጠይቁ ከ45-60 ደቂቃዎች ሊወስድ ይችላል ፡፡ በቃለ መጠይቁ ወቅት ማስታወሻዎች ሊወሰዱ ይችላሉ ፡፡ እንዲሁም እርስዎ ከፈቀዱ አነስተኛ ድምፅ መቅጃ እንጠቀማለን እና ከቃለ መጠይቁ አጫጭር ንግግሮች የጥናቱን የመጨረሻ ውጤት ላይ ሪፖርት ለማድረግ ያገለግላሉ፡፡ እንዲሁምበፈቃደኝነትዎ በፈቃደኝነት ቅጽ ላይ እንዲፈርሙይጠየቃሉ ፡፡ ውጤቶች ይህ ጥናት በሚቀርብበት ጊዜ ይጋራል ፣ ግን ከሪፖርቱ ጋር ስምህ/ሽ አይጠቀስም፡፡

ሊከሰቱ የሚችሉ አደጋዎች / ችግሮች፡ - ከዚህ ጥናት ጋር ተያይዞ የሚጎዳ ነገር የለም፡፡ ነገር ግን ከኤች አይ ቪ ጋር አብሮ የመኖር ልምድዎን የሚመለከቱ አንዳንድ ጥያቄዎችን በመመለስ በስነ ልቦና ምቾት ላይሰሞት ይችላል ከባድ ጭንቀት ካጋጠመዎት እባክዎን ያሳውቁኝ እና ቃለ ማጤይቁን አቋርጣለሁ እና መቀጠል ከተስማሙእቀጥላለሁ፡፡

ጥናቱ ሊኖሩት ሚችሉት ጥቅሞች፡ -በአሁኑ ጊዜ ይህ ጥናት ለእርሶ ቀጥተኛ ጥቅምአያመጣም፣ ግን ከዚህ ጥናት የተገኙ ግኝቶች ፖሊሲ አውጭዎች በተዘዋዋሪ ለእርስዎ ወይምከኤች አይ ቪ ጋር አብረውለሚኖሩ ሌሎች ታዳጊዎች ጠቃሚየሚሆኑ ፕሮግራሞችን ፣ ስትራቴጂዎችን እና ፖሊሲዎችን በመንደፍ ውሳኔ እንዲያደርጉ ሊረዳቸውይችላል የሚል እምነት አለኝ፡፡

የመረጃ ሚስጥራዊነት፡ -ከዚህ ቃለ-ምልልስ የተገኘውመረጃ ሁሉ ሚስጥራዊነትን ለማጠበቅ ይያዛል፡፡ የማንምስምአይጠቀስምእንዲሁምመረጃውበኮድ ይቀመጣል፡፡ ስለእርስዎ የተሰጡመረጃዎች ሁሉ እንደ ቃለ ማጤይቅ ስምዎ እና የድምፅ መዘገብዎ ከማንገ የተጠበቁ ስለሆኑ በዚህ ጥናት በማንኛውምሪፖርት ውስጥየግል ማንነትዎ አይጠቀስም፡፡ ቃለማጤይቁ በድምጽ የተቀረጸውየቃለ-ማጤይቁን ሥራ ለማመቻቸት ብቻ ነው፡፡ የቃለ ማጤይቅዎ የድምፅ ቀረፃ ይፃፋል ነገር ግን የእርስዎ ስምእና ሌሎች የመታወቂያ መረጃዎች አይፃፉም፡፡ የእርስዎ ስምየኮድ ቁጥር ይሰጠዋል እናምይህ ቁጥር በሁሉምሪፖርቶች ውስጥ ጥቅምላይ ይውላል፡፡ ሁሉምየመረጃዎ መረጃዎች በተመራማሪዎቹ የግል ኮምፒተር ውስጥ ባሉ ማለፊያ ቁጥሮች በተጠበቁ ፋይሎች ውስጥ ይቀመጣሉ፡፡ በሪፖርት ማጋራት ወቅት የተሳታፊዎች ስም ወይምአካላዊ አድራሻ ጥቅምላይ አይውልም፡፡

በፈቃደኝነት ላይ የተመሠረተ ተሳትፎ እና ጥናቱን የመተውመብት፡ -የዚህ ጥናት ተሳትፎ በፈቃደኝነት ነውእናምለመሳተፍ ወይምላለመሳተፍ የመወሰን መብት አለዎት፡፡ እንዲሁም ያለ ምንምተጽኖ ከፈለጉ በዚህ ጥናት ውስጥ ላለመሳተፍ ወይምከጥናቱ የመውጣት መብት አለዎት፡፡

ክፍያ፡ -ለጥናት ተሳታፊዎች ምንም አይነት ክፍያ የለም፡፡ ቃለማጤይቁ የሚከናወነው ተሳታፊዎች በሆስፒታል ውስጥበሚታከሙበት ጊዜ ነው፡፡

በፈቃደኝነት ላይ የተመሠረተ ተሳትፎ እና ጥናቱን የመተውመብት፡ -የዚህ ጥናት ተሳትፎ በፈቃደኝነት ነውእናምለመሳተፍ ወይምላለመሳተፍ የመወሰን መብት አለዎት፡፡ እንዲሁም ያለ ምንምጭንቀት ከፈለጉ በዚህ ጥናት ውስጥ ላለመሳተፍ ወይምከጥናቱ የመውጣት መብት አለዎት፡፡

ክፍያ፡ -ከጥናት ተሳታፊዎች ጀምሮ ምንም ክፍያ የለም፡፡ ቃለመጠይቁ የሚከናወነው ተሰብሳቢዎቹ በሆስፒታል ውስጥ በሚታከሙበት ጊዜ ነው፡፡

የጥናት ተሳታፊዎች (ታዳጊዎች) መረጃ-ስምምነት ቅጽ

ከላይ የተጠቀሰው የመረጃ ወረቀት በጥቁር አንበሳ ሆስፒታል ከኤች.አይ.ቪ / ኤድስ ጋር አብረው የሚኖሩ ጎ ታዳጊዎች የሚኖሩበት የህይወት ተሞክሮ ላይ ያተኮረ ሲሆን፤ የጥናቱ ዓላማ እና አሰራሩን፣ ጥቅሞች እና አደጋዎች፣ ሚስጥራዊነት ጉዳዮች፣ በፈቃደኝነት ተሳትፎ እና መብትን የሚገልፅ አንብቤያለው/ተነቦልኛል እናም ተረድችለው፡ እኔ ስለ ጥናቱ የበለጠ ማብራሪያ ለማግኘት ማንኛውንም ጥያቄ ለመጠየቅ እድል ተሰጥቶኛል፡፡ በፈቃደኝነት ለመሳተፍ እስማማለሁ፡፡

የበጎ ፈቃደኛ ስም እና ፊርማ________________________________

ቀን ________________

የጥናቱን ዓላማ አረጋግጣለሁ፣ ሊገኙ የሚችሉ ጥቅሞች እና በዚህ ጥናት ውስጥ ከመሳተፍ ጋር ተያይዘው ሊከሰቱ የሚችሉ አደጋዎች ከላይ ለተጠቀሰው ግለሰብ ተገልፀዋል፡፡

______________________ ______________________________________

ቀን የተመራማሪው ስም እና ፊርማ

Appendix C; English version of Parents'/Guardians' Study Information Sheetand informed consent form

Title: Lived Experiences of adolescents living with HIV/AIDS at Tikur Anbesa specialized hospital, Addis Ababa, Ethiopia.

Principal investigator: Mihret Fikreyesus Yami

Name of the institution: Department of nursing and midwifery, College of Health Sciences, Addis Ababa University.

Hello! I am Mihret Fikreyesus masters of pediatrics and child health nursing graduating student from Addis Ababa University and currently I am doing a research about the lived experience of adolescents living with HIV/AIDS. The research discusses about how HIV status disclosure was, how disclosure to others happen, if there are stigmas and discriminations, about sexual and reproductive life, about coping strategies while living with HIV, their future plan and support services they need.

Purpose of the study: This study's goal is to explore the lived experience of adolescents living with HIV/AIDS, so the result of the research will be useful in attaining improved health care services, to improve the quality of the life of adolescents living with HIV and to further control HIV transmission.

Study procedure: Volunteer participants in this study will be interviewed on a few questions regarding their life experience of living with HIV. Your child's participation is fully based on your and his/her willingness. Actually although you are willing for your child to participate he/she can refuse to participate irrespective of your consent. As all the conversation is up to his/her willingness, he/she is fully entitled to ask, interrupt, skip questions and withdraw from the study any time during the interview. Memos may be taken during the interview. Also with your and your child's approval, our conversation will be recorded with a small recorder and short quotes from the interview will be used in reporting the final findings of the study. In addition you will be asked to sign on the consent form for your child's voluntariness. Findings of this study will be shared through presentation, but your child's name will not be mentioned with the report.

Possible risks/ discomforts: The study is not associated with any harm. However your child might feel psychologically uncomfortable in answering some of the questions associated with your life of living with HIV. In case he/she experiences any severe discomfort please let me know and I will stop the interview and will be continued if your child feels like.

Possible benefits: At the moment, this study will not be of direct benefit to your child, but I hope that findings from this study may help the policy makers to make decisions in designing appropriate programs, strategies and policies that will be advantageous indirectly to you and other adolescents living with HIV in the society.

Data confidentiality: All interview data will be handled so as to protect your child's confidentiality. No names will be mentioned and the information will be coded. I would like to assure you that all information about your child such as his/her name and audio record of the interview will be protected from the public and her/his personal identity will not be mentioned in any report of this study.

The interview will be audio recorded only to facilitate the interviewer's job.The audio recording of your child's interview will be written out but his/her name and other identifying information will not be written. Your child's name will be assigned a code number and this number will be used in all reports. All details of your child's information will be stored and secured in a pass ward protected files in the researchers personal computer. Name or physical address of participants will not be used during report sharing and communication of findings.

Voluntary participation and right to leave the research: Participation to this study is voluntary and you have the right to decide whether your child participates or not. You also have the right not to make participate your child in this study or withdraw from the study if you wish without any worry.

Payment: there is no payment for study participants since the interview is to be conducted while the participants are attending care in the hospital.

Parents'/Guardians' Informed consent form

I read/listened the above information and I understood that it is a study that doesn't harm my child, is based only on willingness and promises confidentiality of responses. Accordingly based on my understanding, regarding my child's participation on the study, on behalf of me without any pressure I reached on the following decision. However this doesn't mean I enforce my child to participate. His/her participation will be assured based on his/her consent. I fully agree and permit my child to participate if and only if he/she is willing.

Name and Signature________________

Date ___________________

Interviewer

I certify that purpose of the study, potential benefits and possible risks associated with participating in this study was explained to the above individual.

Name _________________

Signature_______________

Date __________________

Appendix D; Amharic version of Parents'/Guardians' Study Information Sheet and informed consent form

ለጥናት ተካፋዮች መረጃ

ርዕስ-በኤች.አይ.ቪ / ኤድስ የተያዙ በታዳጊ ዕድሜላይ የሚገኙ ወጣቶች በጥቁር አንበሳ ሆስፒታል አዲስ አበባ፣ ኢትዮጵያ

ዋና ተመራማሪ፡ -ምህረት ፍቅሬየሱስ ያሚ

የተቋሙስምየነርሲንግ እና የሚድዋይፈሪ ትምህርት ክፍል፣ የጤና ሳይንስ ኮሌጅ፣ አዲስ አበባ ዩኒቨርሲቲ፡፡

ጤና ይስጥልኝ! እኔ የአዲስ አበባ ዩኒቨርስቲ የህፃናት ህክምና ነርስ ተመራቂ ተማሪ ምህረት ፍቅሬየሱስ ነኝ እናምበአሁኑ ወቅት ከኤች አይ ቪ / ኤድስ ጋራ አብረውበሚኖሩ ታዳጊዎች ላይ የኖሩትን የህይወት ልምድ በተመለከተ ጥናት እያደረግሁ ነው፡፡ ጥናቱ የኤች.አይ.ቪ ውጤት እንዴት እንደተነገራቸው፣ ለሌሎች እንዴት እንደሚናገሩ፣ ማለሎች እና አድሎዎች ካሉ፣ ስለ ወሲባዊ እና ተዋልዶ ሕይወት፣ ከኤች አይ ቪ ጋር አብረው በሚኖሩበት ጊዜ ስለ ስልቶች መቋቋም፣ ስለወደፊት እቅዳቸው እና ስለሚያስፈልጋቸው የድጋፍ አገልግሎቶች ላይ ትኩረት ያደርጋል፡፡

የጥናቱ ዓላማ -ይህ ጥናት ዓላማውበኤች አይ ቪ / ኤድስ የተያዙ በታዳጊ ዕድሜላይ የሚገኙ ወጣቶች ያላቸውን የኑሮ ተሞክሮ ለመዳሰስ ነው ስለሆነም የተሻሻሉ የጤና እንክብካቤ አገልግሎቶችን ለማግኘት ጠቃሚይሆናል፡፡ በተጨማሪ ከኤች አይ ቪ ጋር አብረውየሚኖሩ በታዳጊ ዕድሜ ላይ የሚገኙ ወጣቶች የሕይወታቸውን ጥራት ያሻሽላል እና የኤች.አይ.ቪ ስርጭትን የበለጠለመቆጣጠር ይረዳል፡፡

የጥናት ሂደት፡ -በዚህ ጥናት ውስጥ የበጎ ፈቃደኞች ተሳታፊዎች ከኤች አይ ቪ ጋር ሲኖሩ ያላቸውን የሕይወት ልምድ በተመለከተ በጥቂት ጥያቄዎች ላይ ቃለ-ምልልስ ይደረግላቸዋል፡፡ የልጅዎ ተሳትፎ ሙሉ በሙሉ በእሱ/እርስዎ ፈቃደኝነት ላይ የተመሠረተ ነው። በእርግጥ ምንም እንኳን ለልጅዎ ለማሳተፍ ፈቃደኛ ቢሆኑም እርስዎ/እሱ ፍቃድ ካልሆኑ ተሳታፊ ተሆንም/አይሆንም፡ ሁሉም ውይይቶች በእሱ/እርስዎ ፍላጎት ላይ የተማሰረቱ በሚሆናቸው በቃለ ማጠይቁ ወቅት በማንኛውም ጊዜ የማጠየቅ፣ የማቋረጥ፣ ጥያቄዎችን የመተው እና ከትምህርቱ የማላቀቅ ሙሉ መብት አለው/አላት፡፡ በቃለ ማጠይቁ ወቅት ማስታወሻዎች ሊወሰዱ ይችላሉ፡፡ እንዲሁምበአንተ እና በልጅዎ ሚረጋገጫ፣ ውይይታችን በድምጽ መቅጃ ይቀዳል እና ከቃለ ማጠይቁ አጨጬር ጥቅሶች የጥናቱን የሚጨረሻ ግኝት ሪፖርት ላይ ይገባሉ፡፡

በተጨማሪም ለልጅዎ ፈቃደኛነት በፈቃደኝነት ቅጽ ላይ እንዲፈርሙ ይጠየቃሉ፡፡ የዚህ ጥናት ግኝቶች በአቀራረብ ይጋራሉ፣ ግን የልጅዎ ስም ከሪፖርቱ ጋር አይጠቀስም።

ሊከሰቱ የሚችሉ አደጋዎች / አለመመቸዎች፡ -ጥናቱ ከማንኛውም ጉዳት ጋር አልተያያዘም፡፡ ሆኖም ልጅዎ ከኤች አይ ቪ ጋር ሲኖሩ ያላቸውን የህይወት ልምድ ጋር የተዛመዱ አንዳንድ ጥያቄዎችን ለመመለስ ሥነ-ልቦናዊ ምቾት ላይሰማው ይችላል፡፡ እሱ/እሷ ምንም ዓይነት ምቾት ካልተሰማት/ካልተሰማው ሲያሳውቁኝ ቃለ መጠይቁን አቆማለሁ እናም ልጅዎ እንደተመቸው እቀጥላለሁ፡፡

ጥቅሞች፡ -በአሁኑ ጊዜ ይህ ጥናት ለልጅዎ ቀጥተኛ ጥቅም አያመጣም፣ ግን ከዚህ ጥናት የተገኙ ግኝቶች ፖሊሲ አውጭዎች በተዘዋዋሪ ለልጅዎ ወይም ከኤች አይ ቪ ጋር አብረው ለሚኖሩ ሌሎች ጎረምሶች ጠቃሚ የሚሆኑ ፕሮግራሞችን፣ ስትራቴጂዎችን እና ፖሊሲዎችን በመንደፍ ውሳኔ እንዲያደርጉ ሊረዳቸው ይችላል የሚል እምነት አለኝ፡፡

የመረጃ ሚስጥራዊነት፡ -የልጅዎን ምስጢራዊነት ለማጠበቅ ሁሉም የቃለ መጠይቅ መረጃዎች ይከናወናሉ። ስሞች አይጠቀሱም መረጃውም በኮድ ይቀመጣል፡፡ ስለ ልጅዎ መረጃ ሁሉ እንደ ስሟ እና የቃለ-ምልልሱ የድምፅ መዝገብ ሁሉ ከማንም ሰው የተጠበቀ እንደሚሆን እና በዚህ የጥናት ሪፖርት ውስጥ የእሷ / የግል ማንነቱ እንደማይጠቀስ ላረጋግጥላችሁ እወዳለሁ፡፡ ቃለ መጠይቁ በድምጽ የተቀረጸው የቃለ-መጠይቁን ሥራ ለማመቻቸት ብቻ ነው፡፡ የልጅዎ ቃለ-መጠይቅ የድምፅ ቀረፃ ይፃፋል ነገር ግን የእሱ / ሷ ስም እና ሌሎች የመታወቂያ መረጃዎች አይፃፉም፡፡ የልጅዎ ስም የኮድ ቁጥር ይሰጠዋል እናም ይህ ቁጥር በሁሉም ሪፖርቶች ውስጥ ጥቅም ላይ ይውላል። ሁሉም የልጅዎ መረጃ ዝርዝሮች በተመራማሪዎቹ የግል ኮምፒተር ውስጥ በሚያልፉ ዋርድ በተጠበቁ ፋይሎች ውስጥ ይቀመጣሉ እንዲሁም ይቀመጣሉ፡፡ በሪፖርት ማጋራት እና በግኝቶች መግባባት ወቅት የተሳታፊዎች ስም ወይም አካላዊ አድራሻ ጥቅም ላይ አይውልም፡፡

በፈቃደኝነት ላይ የተመሠረተ ተሳትፎ እና ጥናቱን የመተው መብት፡ -የዚህ ጥናት ተሳትፎ በፈቃደኝነት የሚገኝ ሲሆን ልጅዎ ይሳተፍ ወይም አይሳተፍ የመወሰን መብት አለዎት፡፡ እንዲሁም ያለ ምንም ተጽኖ ከፈለጉ በዚህ ጥናት ውስጥ ልጅዎን እንዲሳተፉ ወይም ከጥናቱ እንዳያቋርጡ መብት አለዎት፡፡

ክፍያ፡ -ቃለ መጠይቁ የሚከናወነው ተሳታፊዎች በሆስፒታሉ ውስጥ እንክብካቤ በሚከታተሉበት ጊዜ ስለሆነ ለጥናቱ ተሳታፊዎች ምንም ክፍያ የለም፡፡

የወላጆች/አሳዳጊዎች ሚጃ ስምምነት የተደረገበት ቅጽ

ከላይ የተጠቀሱትን ሚጃዎች አነባለሁ/አዳምጫለሁ እናምልጄን የማይጎዳ ጥናት መሆኑን ተረድቻለሁ፣ በፈቃደኝነት ላይ ብቻ የተመሠረተ እና የምላሾችን ምስጢራዊነት እንደሚስጥ ቃል ገብቷል፡፡ በዚህ መሠረት የእኔን ግንዛቤ መሠረት በማድረግ የልጄን ጥናት በጥናቱ ላይ ስለማድረግ፣ እኔ ወክዬ በሚከተለው ውሳኔ ላይ የደረሰኝ ጫና ሳይኖርብኝ ሆኖምይህ ማለት ልጄ እንዲሳተፍ አስገድደዋለሁ ማለት አይደለም፡፡ የእሱ/እሷ ተሳትፎ በእሱ/እሷ ፈቃድ መሠረት ይረጋገጣል። እኔ ሙሉ በሙሉ እስማማለሁ እና ፈቃደኛ ከሆነ ብቻ ልጄ እንዲሳተፍ ፈቅጃለሁ።

ስም እና ፈርማ____

ቀን __________________________________

ቃለ መጠይቅ አድራጊ

የጥናቱን ዓላማ አረጋግጣለሁ፣ ሊገኙ የሚችሉ ጥቅሞች እና በዚህ ጥናት ውስጥ ከመሳተፍ ጋር ተያይዘው ሊከሰቱ የሚችሉ አደጋዎች ከላይ ለተጠቀሰው ግለሰብ ተገልፀዋል፡፡

ስም________________________________

ፊርማ________________________________

ቀን __________________________________

Appendix E; English version of Semi structured interview guide

Code number: _______________

I. Back ground data of participants

Probe

- ✓ Would you be able to tell me concerning yourself? (Age, gender, family make up, financial circumstance, Religion, Educational status, location of Residence, marital status)

II. What does living with HIV means to you?

Probe

- ✓ How do you express living with HIV?
- ✓ How do you feel when you think about your HIV status?

III. Would you be able to tell me how you first know of your HIV status?

Probe

- ✓ Who told you, when, where, what were the conditions? How did you feel when you found out about your status?
- ✓ What do you believe is the correct path for uncovering?

IV. Have you ever unveiled your HIV status to some other individual?

Probe

- ✓ For those to whom you have told, what were your measures for picking those people? What were the conditions? How did the individual react to this news?
- ✓ For those not unveiled to your status, for what reason didn't you reveal to them?

V. Do you have a boyfriend/girlfriend?

Probe

- ✓ How old would she/he say; is he/she aware of your HIV status? Are you in a sexual relationship; Are you rehearsing safe sex? What do you think about HIV transmission and avoidance strategies?
- ✓ What sort of husband/wife do you need in the future, their HIV status?

VI. Have you ever felt criticized or separated because of your HIV status?

Probe

- ✓ On the off chance that so how was the circumstance?
- ✓ By whom did it occur?

VII. How do you cope to living with HIV as juvenile?

Probe

- ✓ Is there any troubles?
- ✓ Do you have any concern? If so what are they?

VIII. What kind of supportive services do you need to get from the nurses that are working in ART services or in the hospital?

Probe

- ✓ What are the good traits that need to be increased?
- ✓ Are there any bad traits in the service that you get? If so what are they?
- ✓ Any recommendations you want to get from services you get in the hospital?

IX. What might be done or other supportive services you need other than the health workers?

Probe

- ✓ From your family, companions, social laborers, teachers and the greater society to ensure that you utilize your maximum capacity?

X. Tell me about Plans about your future?

Probe

- ✓ What would you like to be?
- ✓ Do you intend to make a family?
- ✓ Where do you see yourself in ten years to come?

XI. Is there anything you want to add?

XII. Much thanks to you for your delicate joint effort.

Appendix F; Amharic version of Semi structured interview guide

የኮድ ቁጥር ____________

I. የተሳታፊዎች የኋላ ሚጃ

ማጢይቅ

- ✓ ስለ ራስህ/ሽ ልትነግረኝ ትችል ይሆን? (ዕድሜ፣ ጾታ፣ የቤተሰብ ሁኔታ፣ የፋይናንስ ሁኔታ፣ ሃይማኖት፣ የትምህርት ሁኔታ፣ የመኖሪያ ቦታ፣ የጋብቻ ሁኔታ)

II. ከኤች አይ ቪ ጋር መኖር ለአንተ/አንቺ ምን ማለት ነው?

ማጢይቅ

- ✓ ከኤች አይ ቪ ጋር መኖርን እንዴት ትገልጸዋለህ/ጪዋለሽ?
- ✓ ስለ ኤች አይ ቪ ሁኔታዎ ሲያስቡ ምን ይሰማሀል/ሻል?

III. የእርስዎን የኤች አይ ቪ ሁኔታ በመጀመሪያ እንዴት እንዳወክ/ሽ ሊነግረኝ/ሪኝ ትችላለህ/ያለሽ?

ማጢይቅ

- ✓ ማን ነበረ የነገረህ/ሽ፣ መቼ፣ የት፣ ሁኔታዎቹ ምን ነበሩ? ስለ ዊጤቱ ሲትሰማ/ሚ ምን ተሰማህ/ሽ?
- ✓ ሁኔታውን ለመናገር ትክክለኛውመንገድ ምንድነ ውብለህ/ሽ ታምናለህ/ሽ?

IV. የኤች አይ ቪ ሁኔታዎን ለሌላ ግለሰብተናግረህ/ሽ ታውቃለህ/ሽ?

ማጢይቅ

- ✓ ለነገርካቸው/ሻቸው እነዚያን ሰዎች ለመምረጥ ምን መመዘኛዎች ነበሩ? ሁኔታዎቹ እንዴት ነበሩ? ግለሰቡ ለዚህ ዜና ምን ምላሽ ሰጠ?
- ✓ ሁንታህን/ሽን ላልነገርካቸው/ሻቸውሰዎች በምን ምክንያት አልተናገርክም/ሽም?

V. የወንድ ጓደኛ / የሴት ጓደኛ አለዎት?

ማጤይቅ

- ✓ እሱ/እሷ ስንት ዓመቴ ነው ይላል/ትላለች; ስለ ኤች አይ ቪ ሁኔታዎ ያውቃል? በጾታዊ ግንኙነት ውስጥ ነሽ/ህ; ደህንነቱ የተጠበቀ ወሲብን እየለማመድክ/ሽ ነው? ስለ ኤች አይ ቪ ስርጭትና የማስወገድ ስልቶች ምን ትላለህ/ያለሽ?
- ✓ ወደፊት ላይ ምን ዓይነት ባል/ሚስት ይፈልጋሉ የኤችአይቪ ሁኔታ?

VI. በኤች አይ ቪ ሁኔታዎ ምክንያት ትችት ወይምማ\ያየት ተሰምቶህ/ሽ ያውቃል?

ማጤይቅ

- ✓ ሁኔታው እንዴት ነበር?
- ✓ በማን ነበረ የተከሰተው?

VII. ከኤች.አይ.ቪ ጋር ታዳጊ ሆነው መኖርን እንዴት ይቋቋማሉ?

ማጤይቅ

- ✓ ችግሮች አሉ?
- ✓ የሚያሳስብዎት ነገር አለ? ከሆነ ስ ምንድናቸው?

VIII. በ ፀረ ቫይረስ ህክምና አገልግሎቶች ውስጥ ወይም በሆስፒታል ውስጥ ከሚሠሩ ነርሶች ምን ዓይነት ድጋፍ ሰጪአገልግሎቶችን ማግኘት ያስፈልግዎታል?

ማጤይቅ

- ✓ ሜጩምር የሚያስፈልጋቸውሜ\ካምባሕሪዎች ምንድናቸው?
- ✓ በሚያገኙት አገልግሎት ውስጥ መጥፎ ባህሪዎች አሉ? ከሆነ ስ ምንድናቸው?
- ✓ ከሆስፒታል ውስጥ ካገኘሀቸው/ሻቸው አገልግሎቶች ማግኘት የሚፈልጉት ማኛቸውም ተጩሚሪ አገልግሎቶች?

IX. ከጤና ሰራተኞች ውጪሌላ ምን ሊደረግ ይችላል ወይምየሚትፈልገው/ጊው ሌላ ድጋፍ ሰጪአገልግሎቶች?

ማጤይቅ

- ✓ ከፍተኛ አቅምህን/ሽን ለመጠቀም ከቤተሰብዎ ፣ ከባልደረባዎችዎ ፣ ከማህበራዊ ሰራተኞችዎ፣ ከመምህራንዎ እና ከታላቁ ህብረተሰብ ምን ትጠብቃለህ/ቂያልሽ?

X. ስለ ወደፊት ዕቅድህ/ሽ ንገረኝ/ሪኝ ?

ማጠይቅ

- ✓ ምን መሆን ትፈልጋለህ/ሽ?
- ✓ ቤተሰብ ለመመሥረት ታስባለህ/ቢያለሽ?
- ✓ በሚቀጥሉት አሥር ዓመታት ውስጥ ራስህን/ሽን የት ያዩታል?

XI. ሚጨምር የምትፈልገው/ጊው ነገር አለ?

XII. ለጥሩ የጋራ ትብብረህ/ሽ በጣምአማሰግናለሁ; ፡ ፡

Appendix G; Code book

Table 3: Some of the codes with their respective definitions.

Appropriateness of age	Evaluation of the appropriateness of age when they were informed about their HIV status for the first time.
Advanced telling	Attitude of telling about their HIV status to their future spouses before marriage and sexual intercourse.
Blurred future	Those respondents who don't have positive future about their selves because of the disease.
Bright future	Those respondents who view their future in good eyes
Build family	Those participants who want to get married and have children in the future.
Confused	Feeling of participants about taking their medication before disclosure.
Decision maker	As they live with HIV, it made them to be more decision maker and pass different challenges.
Disclosure with exception	The participants disclose to those who have the same HIV status as them but not to those who are negative to HIV.
Education on stigmatization	The respondent's recommendation about giving awareness about HIV and stigmatization.
Enemy	Considers HIV as their enemy.
Hospitalized	When the respondents have been hospitalized due to An illness caused by HIV.
Illness	Used to describe when the participants were ill at least once because of HIV.
In relationship	If the participants are currently in love relationship or if he/she has a boy/girlfriend.
Incorrect assumption	Those participants who believe they can be cured of the virus if they take their medication appropriately and correctly.
Like normal person	Those participants who believe they can live and can do like a healthy person can live and do.
Never told	Participants who have not told to anyone except families and health care

	workers.
Normal with restriction	They consider themselves as a normal person but there are some restrictions that they face as they have the disease.
Optional HIV status	Those participants who don’t give care whatever their future spouses HIV’s status is.
Perceived appropriate age	The perception of the respondents about the appropriate age to tell children who are living with HIV about their HIV status.
Reason for choosing	Reasons of the participants for choosing their future careers.
Reason for not participating	The reasons given by the participants about not participating in the youth club which is known as tea and coffee among the participants.
Reason given	The reasons given by their parents to the participants for taking medication before disclosure.
Reside with	The person or institution the participants live with currently.
Resilience	When the respondents don’t feel anything even if people talk about their HIV status.
Same HIV status	Those participants who have boy/girlfriend with the similar HIV status.
Similarity believe	The participants believe and talk freely with those who are HIV infected.
Stop medication	When the respondents have stopped taking RVI medications in the past.
Suicide	Thinking and attempting to kill self when being informed for the first time about their HIV status.
Tea and coffee program usefulness	The benefits of participating in tea and coffee programs which is a program they participate once a month and get different kinds of education and communicate with each other.
To be together	The reason for choosing HIV positive spouse for the future
Unaware of status	The participant’s boy/girlfriend is unaware about their HIV status.
Was in relationship	Those adolescents who have started love relationships before but currently they have already broken up.
Wish no discrimination	Participant’s hope of not to be discriminated and stigmatized because of their HIV status among the society.

Appendix F; Atlas Ti report

Code Groups	**Code**
Appropriate way of informing	perceived appropriate age
	appropriateness of age
	advantage of telling younger
	disadvantage of telling younger
	disadvantage of telling older
	advantage of telling older
ART clinic services	benefits of ART services
	tea and coffee program usefulness
	reason for not participating
	bad sides of ART clinics
	additional services in ART clinic
	additional services in tea and coffee program
ARV dugs and health problems	stop medication
	use cigarettes
	pass medication time
	Illness
	Hospitalization
coping strategies	Resilience

	incorrect assumption
	religious support
	family's support
	never told
Current sexual relationships	not in relationship
	no sexual intercourse
	current bf/gf age
	fear of break up
	in relationship
	unaware of status
	same HIV status
	current worries relationship
Disclosing their status to others	fear of being hated
	warned by family
	fear of stigma
	has disclosed to others
	exposing health profile
	spill secrets
	disclosure with exception
	warned by the orphanage
	good friendship developed
	similarity believe

expectations of self	● blurred future ● bright future ● work in some place ● despair of being healed
expression of HIV	● decision maker ● better disease ● secretive ● strong ● accepting what has come ● protect self ● normal with restrictions ● like normal person ● fear of death ● Swallowing medication ● Difficult
feelings towards HIV	● harmful ● sad ● feel different from others ● enemy ● lonely ● bored ● feel nothing

	angry at
	hate HIV
feelings when first informed	die soon
	angry at first disclosure
	cry
	realize it's dangerous
	suicide
	startled
	felt nothing
	worry
	refusal of drug
	ask God
	fight with teachers
	hate people
mode of transmission of HIV	knowledge about transmission
	no knowledge about transmission
	vertical transmission
	horizontal transmission
past sexual relationships	no past history of relationship
	was in relationship
	cause for break up

Perceived spouse	● relationship challenges
	● optional HIV status
	● HIV negative spouse
	● no future for relationship
	● understanding spouse
	● to be together
	● advanced telling
	● Infected spouse
plan towards family	● build family
	● marriage with exception
	● optional future for marriage
Socio-demographic	● educational level
	● Participant’s age
	● reside with
Stigmatization history	● similar society
	● discrimination effect
	● stigmatized by relatives
	● no discrimination history
	● discriminated by students
	● stigmatized by a teacher

- discrimination by educated person

Supports they need

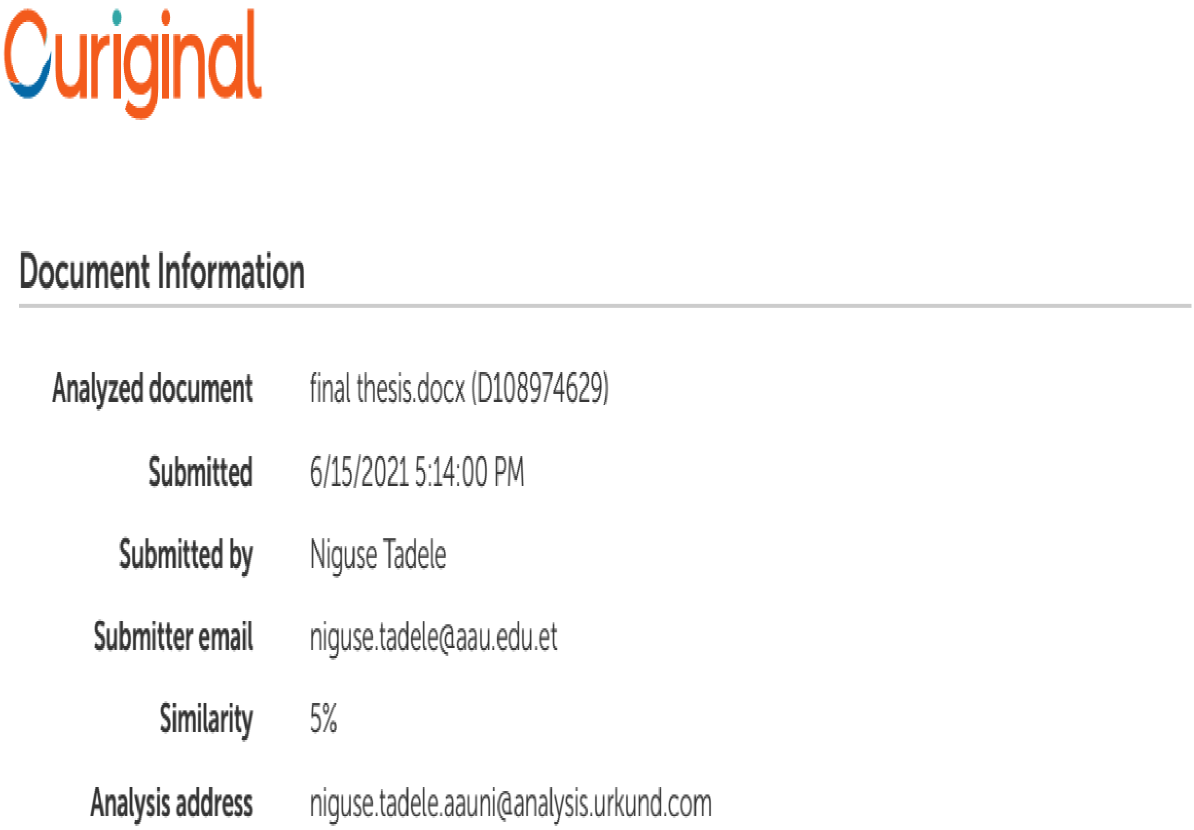
- wish no discrimination
- teacher's responsibility
- education on stigmatization
- supports needed from health workers
- support needed from the government
- relatives support
- supports needed from society
- need support from the government

wants to be

- reasons for choosing
- plan to be

Way of disclosure

- reason given
- confused
- situation at first disclosure
- Age when first informed



Ouriginal

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Similarity	5%
Analysis address	niguse.tadele.aauni@analysis.urkund.com