COLLEGE OF HEALTH SCIENCES

SCHOOL OF PUBLIC HEALTH

DEPARTMENT OF PREVENTIVE MEDICINE

LIVED EXPERIENCES OF PERINATALLY HIV INFECTED YOUTH; THE CASE OF ZEWDITU MEMORIAL HOSPITAL; ADDIS ABABA, ETHIOPIA

BY: NAHOM SOLOMON (BSc.)

ADVISORS: DR. MITIKE MOLLA (PhD, ASSOCIATE PROFESOR)

AND

MRS. BEZAWIT KETEMA (MPH)

A THESIS SUBMITTED TO ADDIS ABABA UNIVERSITY SCHOOL OF PUBLIC HEALTH IN PARTIAL FULFILMENT OF THE REQUIRMENTS FOR MASTERS OF PUBLIC HEATH IN HEALTH PROMOTION AND HEALTH EDUCATION

JUNE/ 2018

ADDIS ABABA, ETHIOPIA

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DECLARATION

I the undersigned, declare that this thesis is my original work, has never been presented in this or any other university, and that all the resources and materials used for the thesis development are recognized and cited, and people who involved in are acknowledged.

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Acronyms and Abbreviations

ALHIV	Adolescents Living With HIV
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral Drug
EDHS	Ethiopian Demographic Health Survey
HAART	Highly Active Antiretroviral Therapy
FHAPCO	Federal HIV/AIDS Prevention and Control Office
HIV	Human Immune Deficiency virus
MSM	Men who have Sex with Men
PAHIV	Perinatally Acquired HIV
PLWH	People Living With HIV
PMTCT	Prevention of Mother to Child Transmission
STI	Sexually Transmitted Infection
SSA	Sub-Saharan Africa
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WHO	World Health Organization

Abstract

Background: HIV continued to be a major global public health issue for the past three decades. Despite the relative control of the epidemic, about one million people had died globally from HIV related cause in 2016 only. In Ethiopia there were 665,116 people who were aged 15 years and above living with HIV in 2017. Youth who acquired HIV from their mothers at birth is an emerging threat for HIV transmission unless control measures are taken before their sexual debut. Learning experiences of these youth is important to address their needs and control HIV transmission. However much has not done in this area. We therefore conducted this study with the aim of exploring the lived experiences of youth who had acquired HIV perinatally to contribute to the HIV prevention and control program.

Methods: We conducted a qualitative study using a phenomenological approach from March to May 2018 at Zewditu Memorial Hospital, Addis Ababa. We purposively selected 16 youth who had acquired HIV vertically. A semi structured interview guide was used to collect data through in- depth interviews. Data were audio taped, transcribed verbatim and translated to English by the principal investigator. The translated data were read and re-read several times and then coded using Open Code version 4.02 software. Basic principles were followed to assure trustworthiness. Study participants were recruited based on their willingness after informed consent and assent. Following interpretative phenomenological analysis; results are summarized with emerged themes.

Findings: Seven males and nine females aged 16 to 22 years participated in the study. Youth in this study feel that they got the disease that they do not deserve to have it. They believed that they benefit more from not disclosing their status than disclosing to people around them because of fear of stigma and discrimination. Half of them have ever had sexual relations and four girls had unprotected sex starting at age of 17-18. Among those, two had unprotected sex with positive partners, one with a partner who has a negative sero-status while the other one did not know the status of the partner. Most are interested to have love mate of the same health status, wish to have purposeful life and play their role in prevention of HIV.

Conclusion: this study found that youth with perinatally acquired HIV had engaged in sexual relation with youth who had both positive and negative-sero-status. In addition, the fact that they do not want to disclose their status because of fear of stigma and discrimination also indicated the need for more work in the HIV prevention program. Challenges related to disclosure, pill-load and fear of what the future will bring in their life should be closely followed to their future life.

***Key words**;- Youth, Perinatally acquired HIV, Mother to child Transmission, phenomenology*

1. Introduction

1.1.Background

The Human immunodeficiency virus (HIV) is a virus which infects cells of the immune system and destroys or impairs their function, leading to "immune deficiency." Acquired immunodeficiency syndrome (AIDS) which is defined by the occurrence of any of more than 20 opportunistic infections or HIV related cancers, is a term which applies to the most advanced stages of HIV infection (1).

HIV/ AIDS remains one of the world's most significant public health challenges, particularly in low-and middle –income countries (2). More children acquiring HIV vertically are transitioning to adolescence and young people. But the global HIV epidemic among them have not received adequate focus where it matters most in their live (3,4).

Youth with perinatally acquired HIV/AIDS is an individual who gets infected with HIV from parents once but stays infected and affected for life. So it is a separate epidemic and needs to be handled and managed separately from adult HIV (5). Many key life events happen during young age, especially adolescence is typically a period of experimentation and engagement in high-risk behaviours (6).

HIV/AIDS is unique from other childhood illnesses in that it impacts populations already made vulnerable through different things and is sexually transmittable. As normative developmental changes of adolescence interact with many unique disease characteristics, HIV positive adolescents and their families require intensive and coordinated multidisciplinary support to help youth manage the behavioral tasks (7).

Adolescents living with HIV have mostly the same dreams and hopes as all other adolescents. Although they often face a number of health challenges in their day- to-day lives, many of the issues faced by adolescents living with HIV are linked to broader psycho-social aspects of their lives. In many ways, their experience of living with HIV provides the best guidance on how to support them to realize their rights and their full potential.(8)

Adolescents and youth are increasingly recognized as a priority on the global agenda as well as in national HIV polices but lacks action and resources (9). With growing numbers of HIV-infected children surviving to adolescence and becoming sexually active, the need for secondary prevention programmes is increasing (4).Taking these into consideration ending AIDS requires to address different factors that continue to fuel the AIDS epidemic (10). As pointed above young people who acquired HIV perinatally needs special attention, so in addressing their health issues and controlling HIV transmission, it is very important to learn how these people are living.

1.2. Statement of the problem

HIV continues to be a major global public health issues (11). Seventy six million people have infected with HIV and 35.0 million people have died from AIDS related illnesses since the start of the epidemic (12). There were about 36.7 million people living with HIV (PLWH) at the end of 2016 with 1.8 million people becoming newly infected and 1.0 million people died from HIV related cause globally(11,12), and 20.9 million people were accessing antiretroviral therapy in June 2017. There were also 19.4 million PLWH and 77 000 new HIV infections among children in Eastern and South Africa in 2016 (12).

Worldwide, AIDS is the second highest cause of death and the leading cause of death among adolescents in Africa. Adolescents are the only age group where deaths due to AIDS are not decreasing (3,13). The estimated number of AIDS-related deaths among adolescents (aged 10–19) has tripled since 2000, which is largely due to the increased number of adolescents living with HIV who were vertically infected. During the period 2005–2014, AIDS-related deaths among adolescents increased by nearly 50 per cent (from 41,000 in 2005 to 60,000 in 2014), while all other age groups saw decreases during the same period (13).

Globally, 81 per cent of all adolescents living with HIV in 2014 were infected via vertical (mother-to-child) transmission (13). An estimated 1.8 million adolescents were living with HIV in 2015, a total that is 28 per cent higher than the comparable estimate of 1.4 million in 2005. Nearly half of those adolescents living with HIV in 2015 were in just five countries with more than 60 per cent (1.1 million) living in Eastern and Southern Africa alone (3,10).

HIV Related Estimates and Projections for Ethiopia showed that 722,248 of people lived with HIV (665,116 were 15years old and above with total prevalence rate of 1.16), 22,827 of new HIV infection and a total of 14,872 people died from HIV/AIDS in 2017 (14). Paediatric HIV population in Ethiopia are mostly older children who were vertically infected (15).

Children and young people face a range of complex issues; they are an important and sometimes forgotten part of AIDS epidemic. Addressing the needs of young people living with HIV and enabling them to live positively is not well done. Many young people live with medical crises and some will need to come to terms with idea of dying prematurely (16,17).

As adolescents living with vertically acquired HIV reach puberty and become sexually active, they carry great risk of transmitting HIV to others and may even result in a second generation of children to which HIV is transmitted vertically (18).

Although HIV/AIDS has prompted increased research interest in adolescents and young adults who constitute about 21% of people living with HIV in Sub Saharan Africa (SSA), young people living with vertically acquired HIV got limited attention. Much of the research

have been confined to the epidemiology of sexually acquired HIV infection amongst 15-24 year olds (18). Since those who were infected from parents are different in many of their issues, understanding their lived experience helps to address their needs and moreover it is a great opportunity to control and prevent HIV transmission (19).

As studies among youth with perinatally infected HIV revealed; they have a lot of issues with regard to their current and future life, families, care givers, school, Medias, treatment, health care facilities, communities and others (18,20,21), and on the other hand they are very decisive population group relative to HIV transmission and prevention as well. There are limited lived experience studies done among care givers of perinatally acquired HIV positive children in Ethiopia (22,23).

Up to my knowledge a study that directly involved young people who acquired HIV from parents in Ethiopia is limited. This study was planned to directly approach youth with perinatally acquired HIV and explore their lived experiences. Why I was interested to study these population group was to learn what their experiences living with HIV since birth looks like and more over to learn their sexual behavior and relation which have big implications with their health and HIV transmission and control as well.

1.3. Significance of the study

Learning the lived experiences of perinatally HIV infected youth help to identify the areas where to focus for promoting their health and empowering them to play their role in prevention of HIV transmission, furthermore it helps to inform the community, health care providers and other health agents. Considering that this study focused on exploring supportive mechanisms, concerns, challenges and sexual behavior and relation of youth's who had acquired HIV from their parents. The information was summarized based on the emerged themes so that it will be utilized by service providers, policy makers and researchers accordingly. Hope the findings will add a value in this important public health issue area and it reflects where to focus for interventions and further studies.

1.4.Basics of the study approach

As it is a major public health concern; the importance of studying HIV/AIDS from different dimensions is unquestionable. This study focuses on young people, specifically youths who had acquired HIV perinatally. As tried to convey above these people have many issues that need attention and call for actions. To do that it is clearly indicated and advantageous to learn directly from themselves. This will be done by applying the right study approach. For this case it is a qualitative study which is more helpful and applicable. As scholars suggest one aim of qualitative health research is to provide a multidimensional understanding of a person's experience of a health condition that goes beyond an everyday or common sense awareness and which leads to a more informed and empathic practice (24,25).

The strength of qualitative research is its ability to provide complex textual descriptions of how people experience a given research issue. It provides information about behaviors, beliefs, opinions, and emotions (26). Of the type of qualitative studies a hermeneutic phenomenological approach was considered for this particular study.

The phenomenological approach aims to develop a complete, accurate, clear and articulate description and understanding of a particular human experience or experiential moment. Findings are allowed to emerge, rather than being imposed by an investigator (27). In the human sphere, it means, gathering 'deep' information and perceptions through inductive, qualitative methods such as interviews, discussions and participant observation, and representing it from the perspective of the research participant(s) (28). This study also follows the socio ecological model to learn the individuals' experiences which are influenced from the individual him/her self, from the community, service centers, policy and programs.

Giving extreme care in moving step by step and in being ever mindful not to delete from, add to, change, or distort anything originally present in the initial "meaning units" of the participant transcripts, data description will be kept faithful as original one (27). Interpretive phenomenological analysis (IPA) approach was followed for data analysis of this study. IPA is concerned with exploring and understanding the lived experience of a specified phenomenon. It has 2 basic tenets: first, it is rooted in phenomenology, attempting to understand details of participants' 'lifeworlds'; their experiences of a particular phenomenon, how they have made sense of these experiences and the meanings they attach to them and second, that the researcher attempts to interpret this meaning in the context of the research (27). So this research was implemented inline to all these study approach principles.

2. Literature review

Looking to different literatures mainly published articles and WHO reports, here under presented HIV/AIDS related pertinent issues mainly related to young people. Accordingly this literature review covers HIV/AIDS overview, HIV/AIDS and young people, Supports, Concerns, challenges, and sexual behavior and relation of Perinatally HIV infected youth under different sections.

2.1.HIV/AIDS overview

Infection with HIV was first identified in the USA in 1981, among homosexual men who developed symptoms of the late stages of the disease today termed Acquired Immune Deficiency Syndrome (AIDS) (29). The world has committed to ending the AIDS epidemic by 2030. How to reach this bold target within the Sustainable Development Goals is the central question. The extraordinary accomplishments of the last 15 years have inspired global confidence that this target can be achieved. UNAIDS recommends a Fast-Track approach: substantially increasing and frontloading investment over the next five years to accelerate scale-up and establish the momentum required to overcome within 15 years one of the greatest public health challenges in this generation (30).

In 2016, UNICEF and partners conceived a 'superfast-track' approach for HIV prevention and treatment for children, adolescents and young women that was endorsed at the United Nations High-Level Meeting on Ending AIDS. The name of the framework, Start Free, Stay Free, AIDS Free, reflects its ambitious targets for 2018 and 2020: eliminate mother-to-child transmission of HIV; reduce the rate of new HIV infections among adolescents and young women; and increase HIV treatment for both children and adolescents (3).

The latest UNAIDS data, covering 160 countries, demonstrate both the enormous gains already made and what can be achieved in the coming years through a Fast-Track approach (30). Sub-Saharan Africa (SSA) has the world's highest prevalence of HIV incidence, with about two thirds, or 68%, of the global total of those infected by the virus living in this region. For example; Botswana has the second highest infection rate in the world (31), with many of the adolescents living with HIV in the country today have been HIV positive since they were born or contracted HIV as infants via breastfeeding. The disease has devastating effects for everyone involved and at all levels of society (32).

2.2.HIV/AIDS and young people

Adolescence is characterized by a period of tremendous change and growth—physically, emotionally and socially. These changes become even more complicated for an adolescent

diagnosed with HIV. Adolescents are not a homogeneous group. Adolescents of the same age can differ in their physical, psychological or social development. There are many developmental differences between a young 10-year-old adolescent and a 19-year-old. These differences affect adolescents' counseling needs and their capacity to care for themselves(33).

Nearly all (95%) children younger than 15 years acquired HIV infection perinatally; in fact, a substantial number of the 2 million adolescents with HIV infection worldwide are thought to be long-term survivors of perinatal HIV infection, but data have not been collected in a way to distinguish perinatal (vertical) and behavioral (horizontal) routes of HIV transmission in this age group (34).

The predominant route of HIV infection in children is MTCT. In the absence of ARV preventive interventions, in nonbreastfeeding populations, 25% to 30% of infants born to HIV-infected women will become infected; the risk increases to as high as 50% for infants with prolonged breastfeeding. Sexual transmission is an important mode of transmission for adolescents. Less common routes of transmission include transfusion with blood products tainted with, percutaneous exposure, and, rarely, HIV-infected caretakers chewing or warming food in their mouths and then feeding it to infants and children (35).

As the HIV epidemic matures, as strategies are developed to prevent mother-to-child transmission, and as paediatric antiretroviral drugs become more widely available, the number of HIV-infected infants will decline, whereas the number of children with HIV infection surviving to older ages will increase for some time (6).

One of the great challenges in HIV prevention is that today's young people have never known a world without AIDS; they did not experience the shocking early days of the "new disease". Improved (access to) treatment has changed HIV and the image of AIDS from a fatal disease to "just a sexually transmitted infection". Many young people are fatigued by prevention campaigns that are outdated or unrealistic (16).

Too often, prevention activities focus merely on the biological or medical facts or provide ideological approaches to sexuality and choice, rather than addressing the needs of young people living with HIV and enabling them to continue living positively (16).

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 (5).

Studies on HIV/AIDS so far done in Ethiopia focused mainly on investigating 1)HIV prevalence and factors associated with HIV infection; 2) prevalence and impacts of opportunistic infections and other comorbidities; 3) sexual and other risk behaviors for

HIV infection; 4) awareness and knowledge about HIV/AIDS and related issues; 5) reproductive preferences and risk behaviors of PLWHA;6) occupational risk exposure and protection; 7) broader social drives of HIV/AIDS; 8) violence and harmful traditional practices; and 9) other existing and emerging research areas (36).

2.3.Supports for Perinatally HIV infected youth

UNAIDS suggest to know local epidemic and scale-up evidence informed, youth friendly programmes accordingly for adolescents and youth, especially young key populations and young people living with and affected by HIV; ensure programmes are tailored to the specific needs of girls, young women, boys and young men, included in national strategic plans, and appropriately costed and earmarked in national budgets (9). Right information, an enabling environment and supportive services help adolescents take informed decisions regarding important health issues and contribute to a better future (5).

Though it is not possible to predict how these young people's health and lives may develop and how HIV will affect their future, many are living fulfilling lives. Some have become parents, most are either working or studying and many see HIV as just one part of their lives, in spite of the fears they have about dying and their experiences of loss (17).

A study from France that explored life satisfaction of perinatally HIV infected Adolescents showed that; on the analog scale (1-10) of life satisfaction, none of the participants rated their satisfaction below 4. The mean rating was 7.05. Those with ratings below 7 attributed their low satisfaction to HIV or to psychosocial vulnerabilities including mother's absence and loss of positive self- image (37%). To the question: -What would you need to approach number 10 and be very satisfied with your life?-, the 20 adolescents who had low life satisfaction expressed the following wishes:

"to be not ill and tired, to be rid of the virus and the disease in order to live a normal life, to be untroubled and relaxed, self-confident as others, to have my mother alive and healthy"(37).

As a study done in Botswana indicated, several positive resources and coping strategies were identified among adolescents living with vertically acquired HIV. To be disclosed to was identified as one of the major positive resources, contributing to several other positive factors, such as knowledge and understanding about their condition and life situation, and improved access to social support. Family, friends and leisure activities were also important positive factors that contributed to well-being. All of the participants saw disclosure as very

important to them, and they emphasized that disclosure should not be delayed, and the importance of openness and presence of their caregivers in the disclosure process (32).

Perinatally acquired HIV positive youths from South Africa and Puerto Rico mentioned their immediate family as the main source of support available. And of the study participants none mentioned any support structure beyond the family and to a lesser extent the school system. Although some participants have extended support from their teachers, it is not enough support for adolescents with perinatal HIV. They need additional support from friends and the community as a whole (21,38). Another study from South Africa revealed the importance of receiving social protection in three key locations for adolescents: school, home and clinic (39).

2.4.Concerns of Perinatally HIV infected youth

Young people living with HIV/AIDS have multiple concerns (17,18,20). Developing and implementing effective and meaningful HIV programmes for young people requires the recognition that adolescence and youth is a time of great psychological, physical and social change at the individual level, where behaviors and perceptions of risk, illness and health are shaped in relation to parents, peers and the wider community (9).

Providing care to adolescents is a multifaceted process in that no two adolescents are the same, but they all require sensitive, flexible, culturally and developmentally appropriate care. For clinicians caring for adolescents, it is crucial to understand that for the eventual success of treatment, it is critical to manage the "whole" adolescent within the context of his/her own economic, cultural, psychological, and family environment (20).

Studies from United Kingdom and South Africa revealed that, the fear of death was one of the common reactions reported by the young people when they were told about having HIV. They reported feeling frightened, feeling a fear of dying and fearing they would die soon. Some young people expressed feeling a need to condense their living into fewer years as they were unsure as to how long they have to live. They expressed needing to live for now and not to look too far into the future (17,18).

A study from America which assessed the Lived Experience of Perinatally Infected Young Adults, reported that, the experience of being exposed to HIV from a very young age was found to be a complex life experience that had a profound impact on the young adults' life (40).

In another study among young people with vertically acquired HIV/AIDS, it was reported that, young HIV-positive women need to make healthier life choices and decrease risky

behaviors; participants emphasized the need for comprehensive programs that extended beyond HIVspecific topics. They requested programs that address a wide range of issues impacting their lives such as self-esteem, selfconfidence, self-worth, living with HIV, sexuality, coping mechanisms, handling adversity, and developing and maintaining healthy relationships.For program structure, the participants reported preferring a combination of individual and group meetings (41).

As HIV/AIDS does not just impact physical health, but rather it can influence all aspects of life, It is suggested that effective prevention and treatment interventions for young HIV-positive people, must extend beyond HIV specific activities and incorporate a gender-specific comprehensive framework that works toward empowering young people sexually, emotionally, physically and socially so that they may lead happier and healthier lives while reducing HIV transmission (41).

2.5.Challenges of Perinatally HIV infected youth

Growing up with perinatal HIV is affected by multiple social and emotional factors (20,21,40). Being positive has adverse effects on the day-to-day lives of these young people(21). For example; The 2016 Ethiopian Demographic Health Survey (EDHS) found that discriminatory attitudes are higher in women than in men, 48% of women and 35% of men thought that children living with HIV should not be able to attend school with children who are HIV negative, while 55% of women and 47% of men would not buy fresh vegetables from a shopkeeper who has HIV (42).

HIV-infected young people face unique challenges when it comes to accepting and treating their diseases. Many young people are in denial, afraid, misinformed or lack familial or social support. Therefore, this age group may benefit from counseling services and supportive care (20,21).

Growing up with HIV poses complex problems as young people begin to explore their sexuality, develop relationships, and take steps to become independent and productive adults. Adolescence is a life stage fraught with change, growth, excitement, and confusion, and the added complication of a serious, chronic, and stigmatized disease presents huge challenges for youth as they grow and mature personally and socially (43).

As per study done among young people with perinatally acquired HIV from South Africa showed, their interaction with friends at home and school is affected by medication.

The participants complained that being on medication makes their live very difficult. They also cited the fear of stigma as a hindrance in their day-to-day lives. The participants indicated that they are afraid of being stigmatized mostly in schools (21).

Disclosure of HIV/AIDS to self and to parents has multifaceted challenges. The adolescent is an emotionally vulnerable age group, and the way in which they will respond to their disease status can never be predicted. On one hand, where sexually infected ones can find it difficult to face their family due to guilt, the Perinatally affected adolescents, on the other hand, can be expected to blame their parents for their situation (5).

HIV infected adolescents have to deal with a school system that is not very responsive to their specific medical, developmental and educational needs. At the very least adolescents had to miss one day of schooling every month to attend the clinic: More serious challenges included, among other things, lagging behind in education, discrimination and isolation at school, hiding to take medication, and teachers breaking confidentiality when they become aware of the student's HIV status. HIV infected adolescents felt discouraged when they could not continue with their education following prolonged periods of severe ill-health (44).

2.6. Sexual behavior and relation of Perinatally HIV infected youth

Adolescents and young adults have been the focus of primary HIV prevention programmes for many years. With growing numbers of HIV-infected children surviving to adolescence and becoming sexually active, the need for secondary prevention programmes is increasing. Sexual identity-building in adolescence is complex and culturally specific, and sexual behaviours are shaped partly by societal norms. WHO suggests strategies or interventions to improve sexual and reproductive health outcomes in adolescents living with HIV (4).

Interventions targeting this group to date have tended to emphasize delaying sexual debut, reducing the number of sexual partners and condom use, rather than providing comprehensive information and support on sexual reproductive health and rights. With an increasing number of young people born with HIV reaching adolescence, it is more important than ever to address the specific needs of this group (16). The importance of understanding and contextualizing the Entrance into sexual activity of adolescents with PHIV has numerous public health implications, including targeted prevention intervention programs (45).

Young people who contract HIV around birth experience unique challenges (16). As they age into adolescence and adulthood, they are confronted with complex decisions regarding sexual behavior. This includes the fears and misconceptions regarding sexual activity, reproductive choices, use of contraception, disclosure of HIV status to partners, and potential child

bearing. Curiosity and interest in sexual relationships is a natural part of adolescence and puberty; however, youths with PHIV face a more complicated entry into sexual maturity, as their disease and its treatment affects their health and can penetrate the central nervous system causing both neurodevelopmental and cognitive delay (46).

A study done in Uganda showed that, a high proportion of young people living with HIV/AIDS had ever been sexually active although a considerable proportion where abstaining at the time of the study. A high proportion of respondents in a boy/girl relationship had not disclosed their serostatus to their partners and only 37% of respondents who were currently in a relationship knew their partners' HIV serostatus. Despite poor disclosure and knowledge of one's partner HIV status, condom use among sexually active respondents was low (47).

Another study from India revealed fifty-nine percent of perinatally HIV positive young people (PHIV+) and 52% of HIV-uninfected adolescents were sexually active. The age at initiation of sexual activity was similar for both groups (median of 14 years) for PHIV+ and median of 14 years for HIVuninfected adolescents. Seventy-five percent of the sexually active PHIV+ adolescents reported unprotected sex compared to 13% of HIV-uninfected adolescents. A significantly higher proportion of PHIV+ adolescents had multiple (>4) sexual partners than HIV-uninfected adolescents (62%) versus 31%) (48).

A study from South Africa indicated that 18 % of HIV-positive adolescents reported having unprotected sex at last intercourse, with girls reporting significantly higher rates than boys (28 % vs. 4 %,). 32 % of HIV-positive girls were Sexually Transmitted Infection (STI) symptomatic compared to 27 % of boys. It is found that high rates of unprotected sex reported by HIV-positive adolescents, and significantly higher rates of virological failure amongst HIV-positive adolescents engaging in unprotected sex, suggesting greater transmission risk to uninfected peers (39).

A study from Ethiopia among adult HIV positives showed that 30.4% of the respondents had engaged in risky sexual practice, inconsistent use of a condom during sexual intercourse within the last 3months prior to the study period (49). A study from East Ethiopian among school youth found that 36.9% of them had engaged in risky sexual behavior(50). And another study from Western Ethiopia reported that over one third of in-school and 41.4% out-of-school youth reported unprotected sex during the 12 months period prior to interview(51).

3. Objective

General Objective

To explore the lived experiences of youth who are Perinatally Infected with HIV and on ART follow up at Zewditu Memorial Hospital, Addis Ababa, Ethiopia: March 20- May 25 /2018.

Specific objectives

- To describe support mechanisms of youth who had acquired HIV Perinatally.
- To explore concerns and challenges of youth who had acquired HIV Perinatally.
- To explore sexual relation experiences of youth who had acquired HIV Perinatally.

4. Methods

4.1. Study area and period

The study was conducted from March 20- May 25 /2018, at Zewditu Memorial Hospital, Addis Ababa. Addis Ababa is the capital city of Ethiopia and the diplomatic center of Africa. It is one of the fastest growing cities on the continent. Its population has nearly doubled every decade and it is currently estimated to be 4 million (52).

HIV related estimates and projections for Ethiopia showed that in Addis Ababa there were 128,912 people living with HIV, 4,221 newly HIV infected people and 1,955 died from HIV/AIDS in 2017. Of the total population with HIV; 128,201 were those 15years old and above with a total prevalence of HIV/AIDS being 5% (14). This study was done at Zewditu Memorial Hospital which was established in 1933 at the current site of Finfine Restaurant hall in Addis Ababa as maternal and child health service delivery facility. By 1971 it was transferred to the then newly built current building. The Seventh Day Adventist Church owned the hospital and run the services until 1984 when it was transferred to the ownership of the government. Addis Ababa City Administration health bureau is now fully in charge of the facility. It is the first ART service delivery site since 2003 and has grown to become the largest HIV care and treatment site in the country (53).

Zewditu Memorial Hospital ART clinic delivers comprehensive HIV/AIDS services in areas of: HIV counseling and testing, provider initiative testing and counseling, prevention of mother to child HIV transmission, ART (adult and pediatric), palliative care, TB/HIV, sexually transmitted infection, post exposure prophylaxis, pre-cervical cancer evaluation and treatment, nutrition assessment and supplementation, laboratory, pharmacy and youth psychosocial support service (53).

As the hospital's report in March 2018 showed; number of adults and children with advanced HIV infection ever started on ART in the hospital was 13336 and number of HIV positive adults and children receiving clinical care in 2017 was 7125; of these 6871 are on ART with 6713 are adults who are 15 or above 15 years old. Those who were 15-24 years were 496 (238 males and 258 females) (53). The hospital was selected for this study because of its long time ART services experience and having many clients; especially of youths.

4.2. Study approach

Qualitative study with hermeneutic phenomenological study was applied (54). As described above this is an approach which is concerned with the life world or human experience as it is lived.

4.3. Study population, participants, and selection technique

Study population

The study participants were youth (15-24years old people) who had acquired HIV perinatally and were on ART follow up during the data collection period. When it is said perinatally acquired; it is to mean that those who were born either at home or health institution but confirmed by health professionals as they had gotten the HIV virus from their parents.

Selection of study participants

One of the public hospitals with long time experience of ART service was purposively selected. This hospital was selected purposely because the investigator understood and hoped that there are a number of youth with perinatally acquired HIV. Study participants were selected with purposive sampling method (applying criterion based and convenience sampling). Their number was limited by the saturation level of the information provided; accordingly most of the information were seen repeatedly when the number of study participants became around 12, so based on that the total number of this study participant was limited to 16 youth.

Different steps were followed to recruit the study participants; first the principal investigator contacted the hospital medical director and then the ART unit focal person. The investigator briefed about the objective and process of the study, discussed with the ART focal person and nurses. During the discussion he had also gotten more information about the ART clinic and the clients. He asked how they confirm whether the person had acquired HIV vertically or horizontally and he understood that it is confirmed by learning from their parents, families, care givers and taking history from the children themselves.

After learning the clinic environment the principal investigator got one volunteer nurse from the ART unit who was able to facilitate the recruitment of study participants and work together throughout the data collection. Since list of youth who acquired HIV perinatally was not found; the investigator made so as the nurse recruit the study participants. Then the volunteer nurse who has long time experience working in pediatrics ART unit was let to deal with youths who had acquired HIV perinatally and who full filled the inclusion criterias. Then she created a line for the principal investigator to contact those young people who were willing to talk with him. The principal investigator, visiting the clinic in different days when youth came for their clinic schedule, again discussed details of study's objectives and processes with each youth, and interview was done accordingly.

4.4. Eligibility criteria

Inclusion criteria

Youth who took part in this study have full filled the following criteria;-

- youth (15-24 years of age)
- youth who acquired HIV through vertical transmission and were on ART follow up at least for a year
- Those who knew their HIV status at least for a year
- Those who gave consent/assent.
- Families gave consent for those who were under 18 years old
- Those who were capable of communicating in Amharic language

Exclusion criteria

- Those who were in serious health problem (in bed) were not part of the study.

4.5. Data collection

Data were collected by in depth interview using semi-structured interview guides. Prior to the actual data collection pretest was done among two youth who fulfilled the criteria; one female and one male. Based on the lesson gained from the pretest necessary adjustments were made on the audio recorder; placing of recorder was adjusted to few distance from the study participant, which made him to speak loud, asking questions were made not linear, the room and sit of interviewee and interviewer were adjusted. All the data were collected by the principal investigator and the nurse who facilitated the contact and selection of the participants was in place to take the responsibility of handling if any emotional reactions happened during the interview. Fortunately there were no emotional disturbances and reactions happened during interview.

The interview was conducted in private room there in the hospital and it was done in Amharic language. The interviewer approached very friendly and created ease environment, started the conversation by introducing each other, gave time and encouraged the participant to feel free and talk openly as just chatting with his/her friends. The interview has taken an average of 34 minutes (26 to 55 minutes) and it was maintained flexible enough in terms of participants' response to questions, not limiting and interrupting them to focus on certain issues linearly.

One interview was conducted in a day, except 2 interviews, so as to transcribe and internalize generated evidences.

During the interview participants were given space to talk about themselves and their experiences living with HIV. In the process, questions and probes were made focusing on their supportive mechanisms they ever have gotten. Following that they were let to discuss about what concerns do they have and what challenges do they have also. Later they were let to discuss about their sexual behavior and relation from past to the future.

Throughout the interview, in addition to audio recording, interviewer also took note about their facial expressions and other nonverbal reflections. In closing the interview session themes of their responses were summarized by the interviewer and told to the participants. Eventually the participants were acknowledged for all their time and cooperation.

4.6. Data quality assurance

For the sake of having a quality data; as described above pretest was done and the principal investigator himself engaged in all activities from interview guide preparation, data collection, checking and transcription of data, and translation too. Additionally data quality was maintained by having notes, quality recorder, ease environment, good voice and communication, critically checking and rechecking of records and transcription. Furthermore colleagues have reviewed the transcription, translation and coding of the data.

4.7. Ensuring trustworthiness

In ensuring trustworthiness the four basic criteria of qualitative study were maintained by following respective principles. In establishing credibility the investigator took adequate time with study participants and since the interviewer was almost at close age with the youth, it helped for the participants to develop rapport, to feel free for talking, to depict their genuine feeling and thought. All interviews were audio recorded and kept for cross checking if needed. Debriefing and feedback from colleagues and advisors were used in managing the data. To assure transferability the study participants were selected purposively who fulfilled the inclusion criteria. The inquire process and findings were described in detail so that any reader of the report will be able to use and researchers may replicate the study at other settings which have possibly similar conditions.

Documents of all the study process including written informed consent, data collection methods, interview records and transcripts were kept for doing audit trial with due respect of confidentiality by colleagues and peers to see the neutrally and dependability. The investigator took one interview document and coded two times, which is a code-recode process, on separate time and checked for similarity of codes for intra coder dependability.

Confirmability was also established by audit trial and words of study participants'(quotations) were used as supplementary in writing the findings.

4.8. Data Analysis

Code book was developed prior to data collection and amendment was done during and after data collection was completed. Analysis of data started and was done simultaneously with data collection. Words of participants and their description of issues were internalized. Immediately after finishing the interview session, information stored on audio recorder was listened repeatedly and transcribed verbatim by the interviewer. The transcribed data was internalized by reading repeatedly and translated to English language. Following the translation, preliminary analysis was done to see for saturation of the information and emerged theme; based on that experience of substance use, condom use and keeping promise got attention relative to preceded interviews. After compiling all translated word documents; coding and categorization were done on qualitative software Open Code version 4.02 (55) based on the already developed and emerged codes.

Following interpretative phenomenological analysis principles (27,56) the lived experiences of participants and meanings they gave to their words were considered in coding and categorization. At first level words and phrases were used to form codes, and then like codes came together and second level categorization was done. Like categories brought together to form a theme which represent the whole idea of the categories (Annex-VI:Theme tree view). Accordingly the lived experiences of youth were interpreted with the four fundamental lifeworld existentials of; lived body, lived space, lived time and lived relationship. The major thematic areas were: sources of supports, concerns and challenges, and sexual behavior and relations of youth with perinatally acquired HIV. Under the umbrella of IPA, thematic analysis was followed to summarize the findings. The quotations which reflect the majorities' view and unique once were used.

4.9. Standard and operational definition

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

Perinatally transmission of HIV is the transmission of HIV from an infected pregnant woman to her newborn child; which occurred during pregnancy, delivery or breastfeeding.

Youth with perinatally acquired HIV/AIDS is youth who gets infected with HIV from parents once but stays infected for life.

Adolescents are persons between the ages of 10 -19

Youth are persons between the ages of 15-24.

Young people are persons between the ages of 10-24 (9).

Unprotected sex is doing sex without using condom

4.10. Ethical consideration

This study was held after getting the required ethical clearance from the School of Public Health Research and Ethics Committee, and Addis Ababa Public Health Research and Emergency Management Core Process. All study activities were abided by basic ethical principles of; respect for person's autonomy, beneficence, non-maleficence, confidentiality and justice to the maximum level. All these were clearly described on the study information sheet and the study participants were able to understand.

With regard to respecting their right, they were fully entitled to ask any questions, skip questions they didn't like to touch and withdraw from the study any time they need. All those in the ART follow up who fulfilled the inclusion criteria and accessed in the data collection period were considered equally to be study participant. Possible benefits of the study were explained and risks were maintained at a very minimum level; interviews were made during their regular clinic visit so they didn't cost extra and their time was managed properly. Care was made not to rouse their bad memory.

Selection of study participants was done by respective health care provider of the ART unit. The investigator passed through following different ethical and legal principles before contacting youths. Prior to directly getting them, a nurse from the hospital ART clinic dealt with youths and families of those who were under18 years of age. Then the investigator conducted free discussion with those who gave him a permission and proceeded through the study with due respect of their rights. There was a study information sheet and consent form which was given to each of them prior to interview so that they have details of the study objectives, possible risks and benefits to decide based on their full information and understanding without any pressure.

The nurse was around during the interview session and was in charge of handling if any emotional reactions happened to the participants, but fortunately there was no. Either before or after the interview, for the sake of disclosure issues and other participants' concern any identification was not let to be disclosed. All the information they shared were kept in strict confidentiality. Finally they were acknowledged, made to return to their prior mood and 50 birr was given for snack.

5. Findings

The findings of this study are summarized based on four thematic areas including sociodemographic characteristics; (1) Reported health status and HIV/AIDS lesson; which involves:- reported health status, feelings about their HIV status, life plan and roles of youth in prevention of HIV, (2) Sources of supports of youth: which involves: family care, clinic care and social support, (3) Challenges of youth: which covers: threat of future life, experience of taking ARV drugs, disclosure of their HIV status and stigma and discrimination, (4) Sexual relation experiences of youth: which involves: youth's sexual relation experience, and youth's sexual relation interest. All of these are elaborated below under different sections. In writing the findings, to keep qualitative nature of the study, the following terms are used:- "most/major:-for more than 9 youth's response, some:-for responses of 5-7 youth, and" few:- for responses of 3-4 youth.

5.1 Sociodemographic characteristics of study participants

Sixteen youth who have acquired HIV vertically have participated in this study. All were Christian religion followers, aged from 16-22 and nine were females. While one of them have learned up to grade 8 and the other one is advanced diploma holder, 14 were students attending their studies at secondary (6) and tertiary levels (8). Eight of them reported to live with their biological parents, while the rest live with either close relatives or fosters(**Table-1).**

5.2 Reported health status and HIV/AIDS lesson of Youth who acquired HIV perinatally

Youth's perceived health status

Most of the study participants have reported that they have good health status; they were happy and believe to reach to better level. Most reflected they used to feel anxiety during their first periods of knowing their status, but later they took it easy. Most have started to take ART in their early age and only one has reported history of using substance but quit after a year. Regarding their lived space; most have lost either both or one of their parents due to that most of them live with single parents, extended families and fosters as well. One of the study participants described his health status as follow:

> *"I feel healthy and I think as I can perform any thing as that of any healthy person" (19 years old male participant-04)*

Some have reported experiences of minor illnesses, especially before initiation of the ARV drug, and three reported sever health problems (anemia) during their ART follow up period which obliged them to be admitted in the hospital.

Table 1: Socio demographic characteristics of study participants for a study of lived experiences of Perinatally HIV Infected Youths; Addis Ababa, Ethiopia; May/2018

Participants	Sex	Age	R/ship	live with	Education	Occupation
P1	M	20	No	Aunt	undergraduate student	student
P2	F	18	No	Fosters	Grade 12	student
P3	M	18	No	Aunt	Grade 10	student
P4	M	19	No	mother	Grade 8	student
P5	F	22	Yes	Father	Advanced diploma	teacher
P6	F	19	No	Aunt	undergraduate student	student
P7	F	17	No	parents	Grade 10	student
P8	M	20	No	mother	Diploma student	student
P9	F	21	Yes	Sister	Grade 11	student
P10	F	19	Yes	Uncle	Diploma student	student
P11	F	16	Yes	Sisters	Grade 11	student
P12	F	22	No	Father	College student	student
P13	M	19	Yes	parents	College student	student
P14	M	20	Yes	parents	College student	private
P15	M	18	No	mother	College student	student
P16	F	18	Yes	Aunt	Grade 8	private

Keys: R/ship= having boyfriend/girlfriend relationship, P= participant, Parents= living with both father and mother

Youth's feeling about their HIV status

Majorities of the study participants have depicted as they don't like to think about their HIV status; some revealed that they feel disturbances and loneliness when they think of HIV/AIDS. Those who expressed such feelings have also reported stress and frustration which affected their lived body and lived human relation. However some have also hope to get cure believing in God and even tried for that in some religious events. 18 years old female study participant revealed her reaction to her status as follow:

> *"You know it is punishment without your fault, so things happening not due to your fault disturb you." (18 years old female participant-02)*

Another study participant has also reflected the following:

> *"There is a feeling I feel as human being; I mean I need to live being healthy as any one, at the beginning I felt as the virus is posted on my face (yehone viresu fitih lay yeteletefe hulu new yemimeslh), I mean I feel as all know my status; What makes me to shock is people's response" (20 years old male participant-14)*

Majorities have reported different emotional reactions by the time when they understood that they had HIV. Some have cried, shocked, isolated themselves and delayed to accept it, but later on they convinced themselves and lead their life well. Here below is one of the reactions:

> *"You know, you don't expect it, you don't expect even your friends may have that. You shock when you hear and again you know it is non curable…… I went to church and cried alone" (17 years old female participant-07)*

Their lived human relation was limited to very close families; most of the study participants have reported that very few people even from families knew their status and they discuss about their health only with health care providers and with one or two family members mainly with parents, sisters and aunts. One unique report seen was; one boy reported that he didn't ever disclose his status for his father and take his drug even hiding him. He did that not to tension his father because his father himself is HIV positive, lost many things including his wife and currently lives alone, and he thought as his son is HIV negative.

Majorities have reflected as they learned about HIV more from school and searching articles by themselves and again they need to learn more. Most of them described it as it is not severe thing as far as people take ARV drugs properly and took it easy relative to other chronic diseases. Most of them depicted that they don't give attention for HIV messages from medias and different channels. Some reported that HIV is not getting emphasis and suggested that it is good if medias work more and focus to change community's attitude and foster awareness about HIV/AIDS. There are also few who don't like to see HIV messages anywhere.

Youth's life plan

Almost all study participants have depicted that they wish to be successful in their life, which is expressed as their lived time. They want to show as they are capable of doing everything. There were also who dream to learn more and wish to help the community. There were youth who dream to be a famous actress and director, psychiatrist, psychologist, engineer, pilot and PhD holder and to be influential person in their area of specialization. An eleven grade girl indicated that:

"I want to be psychologist; I want to work on prisoners and students. I want to work on forgotten people. You know when you close and talk them; you get what you didn't expect. They want to share their ideas but they don't get who hear them. So I will be happy if I reach them and give them what can I do." (21 years old girl)

Another female respondent who is an undergraduate student indicated that:

"I am working and learning. In my education also; as any other person I want to reach to better level. Even I want to be above who has no HIV. If I achieve that, I will get the chance to be an examplenary to others." (19 years old female participant-06)

The other issue most participants reflected on was to get a place where to play and share ideas freely. As mentioned below one of such program currently found is the youth club where they meet every two weeks; but almost all study participants reflected it is not enough; they need more programs adding different events on what is found now, so youth wish for more programs which embrace them. One of the study participants reflected on this as follow:

"I wish if there is a program where I meet people like me (HIV positive youth), at least one day where you breath, where you speak your internal thought and go. It is hard to talk at home where people around you are negative; you fear and even your thoughts don't get each other, but if you are the same, you can talk everything you need, you can say "we."…" (21 years old female participant-09)

Youth's role in prevention of HIV transmission

All study participants believed that they have a responsibility in prevention of HIV transmission. Accordingly they suggested different things they can act on. One of it is to take care of themselves and others. The other thing was they were trying to teach and advise people around them.

"Firstly I should take responsibility for myself and second I should take care of all people around me. I should not let others to be harmed."

(21 years old female participant-09)

The other study participant had also similar thought:

"I will be happy if I can change the community; though not the whole but one who is around me; I mean you start from home then you will move to neighbour. So I will be happy if I could do that, if not I need to continue saving myself and person around me who don't have HIV. Because after this, since it (the HIV) doesn't leave me even if I say it; I feel to continue doing that way." (19 years old female participant-06)

5.3 Sources of supports of Youth who acquired HIV perinatally

Family care

Family is the major source of support revealed by most of the study participants. As indicated above almost all study participants live with their biological families and extended families; even the one who lives with fosters also see them as parents and feel as she is with her father and mother. Most of the study participants reported that they have a nice support and care from their families and even from their extended families as well. Two girls who live with their aunt said:

> *"It is good….., I am living with my aunt. She has also HIV; we are living supporting each other. ……. I have families, I have brothers; all the families know my status, they all support me, they give me all cares." (19 years old female participant-06)*
>
> *"My aunt is my supporter and a very decisive person in my life"*
>
> *(18 years old female participant-16)*

On the other hand there were also few who couldn't get adequate family care even from fathers. A 19 years old girl reported that:

> *"No family care for me, I am living with my uncle (father's brother) since 5 years back and he doesn't care of me. His principle is 'live your own' and doesn't ask me whether I take the drug or not and of my living." (19 years old female participant-10)*

Clinic care

All of the study participants were following their ART service at a unit where they started and it was with respective age based service. Majorities of them have revealed the health care services they were getting and the care providers' approach was one of the most important supports they have in their life time and they have benefitted a lot from the clinic service. Almost all of them have long time follow up experience in this hospital and they know the environment very well. They contact with doctors, nurses and social workers, and they have close relation. One of the study participants described it as:

> *"My doctors are very much family more than what I can tell you; they treat me as sisters and brothers, as mother and father." (18 years old male participant-15)*

Relative to the health care service; study participants have also depicted that; they have flexible clinic appointment so that they can visit the clinic and collect their drug at any working time they need from Monday to Friday including Saturday morning too. Again majorities have reflected that the separation of the ART clinic from other units is comfortable for them.

Acknowledging the good services of the clinic; there were also issues which were suggested to be seen and corrected. Some have reported presences of problems with time management, the service being merely of prescribing drug than addressing their psychosocial issues and no enough laboratory services. Again it was reflected though the clinic appointment is flexible; still some youth reported missing of class due to clinic appointment. For missing the class they take sick leave medical certificate which doesn't disclose their status. They don't like to tell for their teachers about their status rather they create different reasons and tell that for missing the class.

Social support

Another support youth with perinatally acquired HIV had is the support from friends ; youth club is the top of it, which is an edutainment program where youth who had acquired HIV from parents get together every two weeks and learn, play, entertain, share different things and get friends; including boyfriend and girlfriend. The youth club is divided in to two; one for those under 15 years of age and the other for those above 15 years of age. Although all don't participate due to their personal and family reason, those who participate in it reflected as it is good for them and love it.

> *"When we get together; since we share ideas, you may start relationship too. It is as chance, so it is nice. It is very nice for us; from school side and getting friend side it is very nice. For your surprise children who live in the same residence area knew each other here in the hospital. You know I shocked when I see them at first time but later we became best friends. We talk even going to at home; one day in one and the other day in once home." (19 years old female participant-6)*

Another study participant discussing about youth club has also depicted its benefit as follow:

> *"It has much benefit. You get friends, you feel pleasure when you get something yours, you talk with them freely than healthy guys, I mean you feel as you are not alone, no one pointed each other on you, I wait the day we get each other eagerly" (19 years old female participant-10)*

Beyond the youth club; some had supports from their school and local friends, and some teachers. They have reported that their close friends understand them and treat them very friendly.

5.4 Challenges of Youth who acquired HIV perinatally

Threat of future Life

Majority of them revealed they have concerns of their future life relative to; succeeding in education, getting job and forming marriage. They shared their threats with regard to such things:

> *"What concerns me is my life, I mean my future life; I am human being and when you grow and reach at some level you will form family;…… sometimes I feel as I may remain alone; I mean without forming family something. You know the community is yet, doesn't know anything. They don't believe that we are able to do as anyone."*
> *(19 years old female participant-6)*

Forming a marriage is one of the big concerning issues. One of the study participants shared her experience as follows:

> *"You know I am female; actually not only females everyone should form a marriage and have home. So such things frighten me. Even by now when my peers have boyfriend I can't do that. Males ask me but I don't want because I know what I have. I don't want to enter to unwanted things by disclosing myself. It is a threat for my future. How to get a husband? I need child but it doesn't be, it worries me."*
> *(17 years old female participant-07)*

Stigma and discrimination

Almost all study participants have discussed that they are concerned of how people treat them and what place they give for them. They reflected that though it is said people's thought have changed but they disagree with that saying still there is a big problem in the attitude and awareness regarding HIV and people living with HIV. They have reported that they have no freedom to do what they wish freely.

> *"In day to day activities you may meet people and the way people view HIV is not good. I don't know but it is good if community's awareness is changed. It is thought that it is changed but still it is not enough, it lacks much…….there are shocking things; people say 'a person with HIV is stunted, unable to walk, bed ridden and the like'…." (18 years old female participant-02)*

Another study participant had also similar concern:

> *"Many times not merely at work place even at school; if it is known as one has HIV it is difficult to live, work and learn together, so I will be very happy if job opportunity is created for us and if such bad attitude and thought at school and anywhere be corrected." (19 years old female participant-10)*

Stigma and discrimination is both a challenge and concerning issue of majorities of study participants. They articulated that what place people give for HIV positive people is disappointing. A 22 years old female study participant shared what she faced from her close friend as follow:

> *"My female friend…. has bad attitude to the disease; if you ask her what she may do if she has HIV, she says "I kill myself" for your surprize; she uses all my materials including clothes but she doesn't know my status, if she knows that; I know she will not stay with me." (22 years old female participant-05)*

The other participant has also said:

> *"If I disclose my status, I am sure they stigmatize me. So I am living with them hiding myself" (17 years old female participant-07)*

Furthermore participants have articulated that community's offensive attitude and awareness about HIV/AIDS and people living with HIV made them to feel isolated and lack freedom, which altered their lived human relation. Almost all study participants have pointed out that; still there is poor awareness about HIV HIV/AIDS and very offensive attitude to people living with HIV. The following statement depicts this:

> *"Awareness of most people is somewhat lower, actually it is better than formerly but still they lack much, they view HIV as other thing bad and we, we children most of us didn't bring it by ourselves, we inherited from parents; they don't think that, if you see in our family; my father's wife (stepmother) doesn't have good view.*
>
> *(22 years old female participant-05)*

Other study participants have also reflected on issue of community's awareness as follow:

> *"I will be happier if we speak freely (benetsanet bininager des yilegnal), you know expressing our internal feeling, if people's attitude change and if we play equally with them as anyone, I will be happier" (17 years old female participant-07)*
>
> *"Our community is not changed well. For example If you stay around waiting room for a minute you see people (PLWH) wearing eyeglass, covering their face, and trying to hide themselves, which is lack of confidence; it is said the community is changed but it is not changed." (22 years old female participant-12)*

Disclosure of HIV status of Youth who acquired HIV perinatally

Disclosure has two dimensions: - the first is disclosure of HIV status of the youth for themselves and the second is disclosure of their HIV status for others.

Disclosure of HIV status of the youth for themselves

Most appreciated and reported as they have benefitted from knowing their status timely. Their lived time since they knew their HIV status was seen as special and they have depicted that they gave attention and take care of themselves, including drug adherence, after knowing their status. The age when they disclosed for their status ranges from 10 to 17 years of age, most of them have known their status around their 14 years of age; which is expressed as their lived time. Some of the study participants knew their status incidentally when they visit clinic for other medical services and some others knew by enforcing their families to tell them why they always take drug.

About time of self-disclosure; majority agree with when to disclose for children like them should be around age of 15 years old. They suggested this age time because if they knew before that age, they may not well understand and even they may disclose themselves to others. But if it is in their 15 years of age; they believe they are capable of handling everything and they will take care of themselves.

Disclosure of their HIV status for others

Disclosure issue is one of the challenges reported by almost all study participants. Disclosing self-status is seen as difficult thing because most of study participants think that; if they disclose their status they fear there will be rejection, stigma and discrimination from people around them. So they don't support to disclose their status for others. Even they reported that, not disclosing their status for others has benefitted them very much, because they said that they do everything they need freely without any threat of people's judgment, stigma and discrimination. They pointed out that if their status is disclosed for others, they may be judged as they are caught due to bad behavior and sexually. Sharing her experience one study participant reported the following:

> *"Sometimes when you go at hospital and sit at waiting room people around you judge you; you know they consider you as bar lady and the like, even they ask you for such things there. One of my experiences was; one time when I was at waiting room, a woman on my side asked me if I got it due to sexual contact."*
>
> *(21 years old female participant-09)*

On the other hand not disclosing self-status has also created different problems on their day to day activities, affecting their relationship and drug adherence. One of the study participants shared her experience as follow:

> *"Because of not disclosing this thing (not disclosing HIV) I faced a problem one time. There was a blood donation program in our school and all my friends registered and*

pushed me to do so. They challenged me much, I tried to convince them by creating other reason; I said, I fear needle and begged them to leave me, even I cried saying please leave me in the name of your mother. You know, you may be embarrassed in such things. if I get tested there; we would take the result together, so my friends might know my status. You know in such things it is difficult."

(17 years old female participant-07)

Another male study participant has also shared his experience as follow:

"You know when you go to other health centers, you have to tell your status…….If I have minor illness first I will go to the village health center, when you go there you have to tell. You know sometimes it is hard, you tell with difficulty (amteh new yemitnagerew)" (20 years old male participant-01)

Experience of taking ARV drugs

Regarding the medication; majority of them have reported experience of; drug load, bad taste, side effects and being boredom of it. Some have said that they miss and or quit their program with their friends and return home for taking drug. Due to such and the like things, majorities have reflected that they have difficulty of life.

"When you swallow the drug it has headache (medhanitun sitwt yazorhal minamn). I don't need to pass my time in that way." (20-years old male participant-01)

Other study participants have also shared their experience of taking the ARV drugs as follow:

"I wish if the drugs load is at minimum, again if you see the drugs most of them are big in size and difficult for handling. It is good if sweety taste is added on them."

(22-years old female participant-12)

"Around 2 years back I was admitted to hospital for a case of anaemia. They told me that it was due to the drug's side effect and the drug was changed, after that I am fine" (16 years old female participant-11)

They have also conveyed as they experience challenges related with taking their ARV drug. Almost all reported that they take their drugs secretly in private area; they don't dare to take if people are around them. Due to that some of them reported experience of not taking the drug on time to missing for days. Some use different mechanisms to hide from others.

"I take it (the drug) hiding from others, for example in a bus I turn myself to window, cover myself with bag and take my drug…… my mother usually says me 'people shouldn't see'" (19 years old male participant-04)

Another female study participant has also shared her experience as follow:

"I don't dare to take my drugs when my friends are with me. Sometimes I skip my schedules, there were many times in which I missed my drugs for 2days and there were also times when I took my drug with an hour time difference from my regular time; even when relatives come to our home I wait till they leave the home or I take hiding from them in separate private area" (17 years old female participant-07)

On the other hand majorities have reflected as they heard a rumour of; there is a drug which is in injection form and be given every six month, so they are dreaming of it to come for them.

"The drug is difficult, so I heard there is an injection which can be given once every six month so I will be happy if I get that" (20 years old male participant-01)

5.5. Sexual relation experiences of youth who acquired HIV perinatally

Sexual relation experiences of youth

Half of the study participants ever didn't have a boyfriend or girlfriend and didn't have ever engaged in sexual contact. The rest have ever had boyfriend or girlfriend. Two of those (one female and one male) who had had mates faced rejection due to their sero-status; their friends were HIV negative and were not willing to continue with them. A female study participant who faced this remembers it as:

"One time I engaged to a relationship quietly, then when you stay long time and the relationship became strong you fear, at the end I told him but then the feeling was very bad….. he used to say "what is the problem, as anyone something" but we human being since we don't live what we speak, when you told as you are HIV positive the response is very bad." (19 years old female participant-06)

Four of the study participants, who were females, have ever practiced sexual intercourse with their boyfriend without condom. All reported that they have disclosed themselves before having a sexual contact. Three of them started it on their 17 years of age and the other on her 18 years of age. Two did it with HIV positive partner, one did it with HIV negative and the other did it with whom she doesn't know his status. Regarding condom usage though they have knowledge to use and believe in; they ignored it due to their partners' unwillingness. They stayed together from 3 months to more than 3 years. One of the study participants who engaged in sexual contact with her HIV positive boyfriend reported that:

"We were at fire age and we did it for satisfying our sensation….. we stayed for three months in one home like husband and wife……..we did it (sexual intercourse) without condom……..(laugh)…….initially we didn't make any care; he(partner) said

"since we are the same(HIV positive) there is no need to do any care"(no need to use condom)." (21 years old female participant-09)

The other girl who has changed her sexual partner after staying one year with the other said that she accepted everything her partners said because she loved both the current, who is HIV positive and the ex-boyfriend, who didn't know his status.

"I didn't hide him anything, I told him all and he believed in it. So it is difficult to go back for one who believed in….. we didn't use condom… what is advised is to make it in condom,……it has no problem for me to use condom but you know, you should keep others' feeling also, so since he didn't like it(condom) we didn't use."

(19 years old female participant-10)

Sexual relation interest of youth

Almost all study participants believe in disclosing their HIV status before starting sexual relation. Majority of those who didn't start any sexual relation looked for getting a boyfriend or girlfriend. But there were differences on when to start forming a relationship; some preferred to delay up to getting job and their age reaches last of twenties, and some said they are okay any time if they get. Regarding their thought about whom they will marry; majorities reported as they prefer the same health status, but they also well come who accepts them even if he/she is negative for HIV.

"For the future it is God who knows. We are human, we try. You don't sit saying I don't love. I should not hurt that person and he shouldn't also. I will be happy if we are similar (both HIV positive)(bihon bihon and aynet binhon des yilegnal). But if not just if he has awareness and accepts me that is also not bad"

(19 years old female participant-06)

There were also who fear they may not get a girlfriend or a boyfriend. Majority of them were in need of getting a friend but reported that they had a concern where and how to get their mate.

"I think a guy like me (who is HIV positive); but it is difficult to get that. You know love is incidental, so it is hard to get a person like you. Sometimes I moved around here (the hospital) saying my fate is here. But again I say it is not something I could get looking for it. If I get someone who is the same with me (HIV positive) it is okay otherwise I prefer to be alone." (21 years old female participant-09)

Most of the study participants fear they may not get what they want and again they are afraid of rejection even after getting whom they love.

6. Discussion

In this study we found that youth who acquired HIV through vertical transmission knew their status at an average of 14 years ranging between 10 and 17 years of age. The youth appreciated that knowing their status at age 15 is preferable as they are sort of matured and also helps them to protect others from HIV. Youth with HIV also indicated that thinking about their status results in bad feelings hence they prefer to ignore it and hope the future will bring innovative medicine and they also leave their fate to God. Youth do not want to disclose their status to others, fear of stigma and getting a partner who has similar status are some of the concerns and challenges they had. Some already have engaged to sexual relation, even unprotected sex and the rest looked for having mates preferably of the same health status.

Most of the study participants have conveyed that they have good health status and they are happy with their life, they hope to reach to a better level or to a level that they aspire and lead purposeful life. This may result from their adherence to their treatment and getting adequate supports. Studies from Kenya, USA, Sweden and South Africa also showed similar report from Adolescents who had acquired HIV from their parents (20,40,57,58). Although some of these study participants reflected feeling of loneliness and loss of hope no one mentioned about death. This is contrary to a study from United Kingdom where similar population group have reported living with dying and living with loss (17). This difference might be due to exposure difference to death and loss of family member from HIV/AIDS. That means those who live in fear of death and loss might have much experiences of family death.

All participants of this study have reported a benefit from knowing their HIV status and strongly appreciated children should learn their status timely. Knowing self-status helps for them to feel more responsible and take care of their and others health too. This finding is similar with studies from Botswana, South Africa, and Puerto Rico where similar population groups have depicted the same self-disclosure timing and benefit from it (18,32,57,59). When it is said self-disclosure it is important to make it in plan than leaving children to learn about their HIV status incidentally when they visit health care facilities for other medical services or leave them to learn by their own or hearing from somebody else.

Few of the study participants knew their status in their early age, when they are around 10 years old, and they are happy to know their status by that age level. Contrary to this a study from USA showed that children who knew their status in their early age faced complex life (40). This difference might happen due to sociocultural differences; where the youth in the

USA might disclose their status to self and to others same time, but here mostly disclosure remains in the hands of children and since others might not know their status they might not confront with community's reaction to their status.

Participants indicated that they had different reactions when their status was disclosed for them by caretakers. Some reported crying, shocking and not believing what they have heard. this finding is consistent with studies from United Kingdom, Kenya, USA and South Africa (17,18,20,40,57), where similar population group reflected the same reactions to their self-disclosure. Others who used to suspect and collect information about HIV/AIDS earlier in their long time drug intake didn't conveyed serious emotional reactions. As noticed from them children who learned of their status little by little through different levels may not face complex feeling in the final disclosure. That means children should learn about HIV/AIDS from their childhood age and their status should be told when they are matured and are capable of managing themselves.

Regarding the sources of supports of youth with perinatally acquired HIV; families and care givers take the lion share. As most of these study participants revealed families are the very important source of support and strength in their life. Studies from Botswana and South Africa also reported same finding that family care is an important source of support for adolescents with perinatally acquired HIV (21,32). However there are also who couldn't get adequate care from their families even from their fathers. In this study it is identified that there are families who don't care for their children, which could be due to negligence and or forming another marriage.

The health care services and the service providers' approach were other major sources of supports reported by almost all study participants. This finding is consistent with studies report from Kenya, Sweden and Ethiopia (20,58,60). That of Ethiopian study depicted care givers of children with perinatally acquired HIV feel rest and hopeful due to the support they are getting from health care providers. This implies that if the health care services are accessible enough and accompanied with improved friendly services, they will produce tangible health outcome among such population group which help them to have healthy and secured life.

Youth club, which is an edutainment club of youth with perinatally acquired HIV where they get together every two weeks and learn, share ideas, play together and is an opportunity for getting boyfriend and girlfriend, is another major source of supports. All those who

participate in the program clearly pointed out that they have benefitted from it and think for more gains from such programs, wishing it should be more accessible for all people with similar status. This is consistent with different studies from the country and abroad. Care givers of children with perinatally acquired HIV, from Addis Ababa and Oromia Regional State, have also depicted that their children have liked and benefited from peer supporting group (60). Again a study from Botswana also revealed similar program in which adolescents with perinatally acquired HIV enjoy and appreciate such program (32).

UNAIDS also suggest to know local epidemic and scale-up evidence informed, youth friendly programmes accordingly for adolescents and youth, especially young key populations and young people living with and affected by HIV; ensure programmes are tailored to the specific needs of girls, young women, boys and young men, included in national strategic plans, and appropriately costed and earmarked in national budgets (9). So similar to this and other studies, this study has also identified one of the programs which are important and applicable for youth living with HIV is youth club.

Regarding clinic appointment and academic class; Most of these study participants can visit the clinic at a time when it is convenient for them. That is the good thing of the hospital where this study was done because they have flexible clinic schedule which helps clients to arrange their time. However there is also missing of class by few of them and it is in small scale relative to what is reported from Kenya, where adolescents obliged to miss class every two months consequently (20); So considering additional working time; like accessing the services after end of class and whole day of weekends could be options of solutions.

As per the study finding; youth with perinatally acquired HIV need a place which gives them freedom and someone with whom they talk freely. But they are not doing that as they need. This is because there is no either formal or informal channel open for them. Similar report was seen in Sweden (58). So as encouraging response is seen from such programs; like the youth club, considering more edutainment programs is important to promote their health and help them to live lovely life.

Many challenges were reflected in this study. One of these is medication issue on which most complain of as they are fatigued of; drug load, unpleasant taste, side effect, life-long treatment and others. Due to such factors their adherence is being challenged. Care givers of children with perinatally acquired HIV in Ethiopia also reported their children are tired of taking the drug (60). Similarly adolescents with HIV from South Africa have also reported

their interaction with friends at home and school is affected by medication, they complained that being on medication makes their live very difficult (21).

Disclosure to others is one of the major concerning and challenging issues of youth living with perinatally acquired HIV. As pointed out above almost all appreciated to know their status timely but most of them reported that except for very few close friends, they don't like to disclose their status for others. It is because beyond stigma and discrimination they fear people may accuse them as they brought it due to their bad behavior; by sex. Studies done among the same population group in Sweden, South Africa and Kenya also revealed similar finding (21,32,44,57,58). So they prefer to hide themselves and even hesitate to tell health care providers whom they visit for other medical cases. Even care givers of children with perinatally acquired HIV in Ethiopia reported experience of stigma and discrimination from people around them, for that reason majorities have reported to hold their status in secret (60).

As depicted by most of the study participants there is a fear of stigma and discrimination. Although most of them didn't disclose themselves to the community, reported as they live in a threat of they may be stigmatized and discriminated. The fear results from some experiences but for majorities it is their perception from what they have seen and heard in their community. Though stigma level is high, there is similar report from a studies done in kenya, South Africa, USA and Sweden, where adolescents with HIV have fear and anxiety related with stigma and discrimination, and prefer to handle it in secret, not disclosing to others (18,20,40,44,57,58).

Ethiopian study among care givers of children with perinatally acquired HIV revealed there is a big concern and challenge of stigma and discrimination for themselves and their children too (60). It is also found in the present study that youth reported they have threat of rejection and stigma from people around them. This might happen due to low awareness about HIV/AIDS and misunderstanding about its mode of transmission. Another study in Ethiopia, which focused on stigma index have also identified different level of stigma and fear related with that of people living with HIV (61).

Although the 2015-2020 Ethiopia HIV /AIDS prevention care and treatment Strategic plan showed one of the main strategies was to raise knowledge about HIV/AIDS prevention methods, and reduce stigma and discrimination, as this study has also identified there is still a fear of stigma and discrimination which demands strong work to bring tangible change

(62). Supporting this the 2016 Ethiopian Demographic Health Survey (EDHS) has also found that there are a discriminatory attitudes where 48% of women and 35% of men thought that children living with HIV should not be able to attend school with children who are HIV negative, while 55% of women and 47% of men would not buy fresh vegetables from a shopkeeper who has HIV (42).

In a condition where there is such offensive attitude it is difficult to manage HIV/AIDS. UNAIDS has also planned to eliminate stigma and discrimination by 2020 but still it is a big issue (63). Whenever youth with perinatally acquired HIV fear and hide themselves the consequence will not be good because it may affect their entire health condition including ART adherence, social interaction and again may lead them to engage in risky behaviors like substance abuse and unprotected sex. So it is important to encourage them to be confident and foster the community's awareness to have positive attitude and empower them to play their role in care of people living with HIV/AIDS and prevention of HIV transmission.

With regard to sexual behavior and relation; as described above, there were who didn't have mates and or didn't have sexual contact experience and there were also who did have both. It is indicated that those who didn't engaged in romantic relation have reasoned out that is because their age is yet and others conveyed it is because they didn't get the opportunity to get mates they need. The four girls who experienced sexual relation reported that they engaged to unprotected sex to keep their partners interest. However they said that they know what is right is to make it with condom but since their partners didn't like with condom, they did that not to miss their loves. This is one of the challenges showing still women are not deciding on their issues. This sexual behavior and relation is consistent with a study done in Uganda (64). So this calls for action as WHO suggests there should be strategies or interventions to improve sexual and reproductive health outcomes in youth living with HIV (4).

Majorities of study participants reflected that their plan and principle regarding their sexual relation is to disclose their status for their mates before passing to sexual intercourse. This is consistent with a study finding from similar population group in South Africa (18). But there are also few who fear rejection and stigma if they disclose their status for their romantic partners. Another study from South Africa also revealed similar finding in which adolescents with perinatally acquired HIV fear and feel anxiety when they think of disclosing their status for their friends (57).

In this study it is indicated that most of the study participants have depicted their preference for romantic relation is to be with one who is similar with them in his/her health status but they also well come one who is also HIV negative and willing to accept their status in full heart. And very few said they will never marry HIV negative person. Although how much they stick to their promise is in a question mark; because even those who said that have also passed through experience of romantic relation with HIV negative person and unprotected sex, this level of feeling responsible for others is encouraging and it might result from families' and health care providers' education. So this calls for more actions to be taken and work strong to foster their awareness and positive thought regarding their sexual behavior and sexual relation.

This study explored the lived experiences of youth who had acquired from parents and identified the focusing areas. The findings will be an input for further studies and strategies to take actions for improving the health care services of such population groups and further more empowering them and the community, the care providers and agents to control and prevent HIV transmission.

Strengths of the study

Reaching such neglected population group and getting their voices; especially of the most important but sensitive issues through in-depth study with application of phenomenological approach is the strength of this study.

Limitations of the study

This study is not out of limitations; it was only dependent on youths' response; missing parents, care givers, health care providers and others view. Again this study was not entirely on natural setting and it was limited to one setting, which is urban and hospital level. The study being done at health care facility might have influence on participants' responses and there might be social desirability bias. Additionally all those who participated in the study had care givers; almost all from families, so this might also have a bias in their lived experiences.

Conclusion

In this study it is revealed that youth with perinatally acquired HIV have reoprted good health status, and wish for better life, have benefited from timely knowing their HIV status, have supports mainly from families and clinic, which has an encouraging implication in their overall care however they have also concerns and challenges with regard to disclosure, how to form marriage, fear of stigma and discrimination. Because of such issue most prefer to live hiding themselves, even missing their drugs and failing to disclose their status in their sexual relation too, which has a big implication and may result in unwanted consequences with regard to their health and more over with HIV transmission.

It is revealed that there were youth who engaged in unprotected sex. Although most expressed as they take care of themselves and others in their sexual relation, practically they lag to do so and it is witnessed that those who engaged in sex failed to pass through safe sexual relation. So this calls for actions because giving attention for such population group has a double advantage of improving their health as well as empowering them to play their role in prevention of HIV transmission. Furthermore the community should be aware and look in broad about the HIV transmission and cautions that should be taken.

Recommendations

Based on the study findings the following recommendations go to specific actors:-

- For the hosting hospital;-
  - ✓ Being the encouraging things as there; it is recommended to foster the services about psychosocial, reproductive health and sexual relation issues.
- For Addis Ababa HIV/AIDS prevention and control office, Addis Ababa Health Bureau, and Federal HIV/AIDS prevention and control office, NGOs and other institutions working on HIV/AIDS:-
  - ✓ To work on fostering communities' awareness about HIV/AIDS.
  - ✓ Look for concrete work on reproductive health and sexual relation issues of HIV positive youth who acquired it from parents.
- For researchers:-
  - ✓ Further studies which involve parents, care givers, service providers and stake holders with more strong study methods; possibly mixed and cohort studies, to address issues of HIV positive people who had acquired from parents.

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Annexes

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

Greetings! I am Nahom Solomon a masters of public health student from Addis Ababa University, currently am doing a health study about HIV/AIDS and related health issues, specifically among youths who acquired HIV from their parents. The study concerns about supportive conditions, concerns about, related challenges, and sexual behavior and relation of youths, generally which is about lived experiences of those youths who are on HIV treatment follow up.

Aim of the study:- Its aim is learning the lived experience of youth who acquired HIV perinatally, so that the finding will be helpful in designing better health care services to improve the health status and control HIV transmission.

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

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

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

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

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

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

Nahom Solomon
Cell phone:- +251941246518
Email:- nahomsolomon83@gmail.com
Addis Ababa University School of Public Health

Study participants' (youth's) Informed consent form

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

1. I fully agree to participate

   Signature_____

   Date _____

Interviewer

I assure that I informed and took the consent

Name: _____
Signature: _____
Date: _____

Annex-II; Parents'/Guardians' Study Information Sheet

Greetings! I am Nahom Solomon a masters of public health student from Addis Ababa University, currently am doing a health study about HIV/AIDS and related health issues, specifically among youths who acquired HIV from their parents. The study concerns about supportive conditions, concerns about, related challenges, and sexual behavior and relation of youths, generally which is about lived experiences of those youths who are on HIV treatment follow up.

Aim of the study:- Its aim is learning the lived experience of youth who acquired HIV perinatally, so that the finding will be helpful in designing better health care services to improve the health status and control HIV transmission.

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

Rights of the participants:- 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.

Confidentiality of the study:- In any means the information he/she gives will not be used for other purpose beyond this study and always be kept confidential. During the interview, again based on his/her willingness, I will use an audio recorder, which means that what we talk about during the interview will be recorded. This is so that I can remember what we talked about. Your child's name or other identification will never be mentioned in the study. The audio tape will be kept locked in a cabinet in my house and only the researcher will be allowed to listen to the audio tape. It will thereafter be destroyed.

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

Risk of the study:- His/her participation has no risk, in all means he/she is free of any harm and for that the researcher is responsible and accountable.

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

Nahom Solomon
Cell phone:- +251941246518
Email:- nahomsolomon83@gmail.com
Addis Ababa University School of Public Health

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.

1. I fully agree and permit my child to participate if and only if he/she is willing

Signature_____

Date _____

Interviewer

I assure that I informed and took the consent

Name _____

Signature_____

Date _____

Annex-III; Amharic version of study information sheet and informed consent form

<u>የጥናት ተካፋዮች መረጃ</u>

ጤና ይስጥልኝ! እኔ ናሆም ሰለሞን በአዲስ አበባ ዩኒቨርሲቲ የሕብረተሰብ ጤና የሁለተኛ ዲግሪ ተማሪ ስሆን በአሁን ሰዓት ስለ ኤች አይ ቪ ኤድስና ተያያዥ የጤና ጉዳዮች ጥናት በማድረግ ላይ እገኛለሁ፡፡ ጥናቱ በተለይ ኤች አይ ቪ ከወላጆቻቸው የያዛቸው ወይም ከውልደታቸው ጀምሮ ኤች አይ ቪ ያለባቸውን ወጣቶች ስለሚገጥማቸው የጤና ክብካቤ ጉዳይ፤ ስለሚያሳስባቸው ጉዳይ፤ ስለሚገጥማቸው ችግሮችና ፆታዊ ባህሪና ግንኙነት ላይ ያተኮረ በጥቅሉ የህይወታቸውን ልምድ መረዳት ነው፡፡

የጥናቱ ዓላማ፡-ከውልደታቸው ጀምሮ ኤች አይ ቪ ያለባቸውን ወጣቶች የህይወታቸውን ልምድ ማወቅ ሆኖ የጥናቱ ውጤትም የጤናው ክብካቤ የተሻለ ይሆን ዘንድ እና የኤች አይ ቪ ስርጭትን ለመቆጣጠር ለሚደረገው ስራ አጋዥ እንዲሆን ማድረግ ነው፡፡

የጥናቱ ሂደት፡- ጥናቱ ዕድሜያቸው ከ15-24ዓመት ያሉትን የሚያጠቃልል ሲሆን፤ አንተ/አንቺ ከሌሎች በዚህ ጥናት የተካተትከው/የተካተትሽው እንዲሁ በአጋጣሚ እንጂ ምንም የተለየ ትኩረት ተሰጥቶ አይደለም፡፡ ጥናቱ በቃለ ምልልስ ብቻ የሚያልቅ እንጂ ምንም ዓይነት የደምም ሆነ ሌላ ምርመራ አይኖረውም፡፡ ቃለ ምልልሱ ቢያንስ 1ሰዓት ያክል የሚፈጅ ሲሆን ምናልባት የተዘለለ ሀሳብ ቢኖር እንደ አንተ/አንቺ ፈቃድ በሌላ ቀን ተመልሰን ልንነጋገር እንችል ይሆናል፡

የጥናት ተሳታፊዎች መብት፡-በጥናቱ ተካፋይ መሆን በአንተ/በአንቺ ፈቃድ ላይ ብቻ የተመሰረተ ነው፡፡በቃለ ምልልሱ ወቅት የፈለከውን/የፈለግሽውን ጥያቄ ማንሳት፣ ቃለ ምልልሱን ማቋረጥም ሆነ መመለስ የማትፈልገውን/የማትፈልጊውን ሀሳብ መዝለል ይቻላል፡፡

የጥናቱ ምስጢራዊነት፡-ይህ አንተ/አንቺ የምትሰጠው/የምትሰጪው መረጃ በማንኛውም ሁኔታ ከዚህ ጥናት ውጪ ለሆነ ጉዳይ አይውልም፤ ምስጢራዊነቱም ሁል ጊዜ የተጠበቀ ነው፡፡ የአንተ/አንቺ በጥናቱ ተካፋይ ስትሆን/ስትሆኚ ስምህንም/ስምሽንም ሆነ ሌላ መለያህን/መለያሽን መግለፅ አይጠበቅብህም/አይጠበቅብሽም፡፡ በቃለ ምልልሳችን ወቅት የሚነሱትን ሃሳቦች ለማስታወስና የበለጠ ለመረዳት ያግዘኝ ዘንድ ማስታወሻ የምይዝ ሲሆን በተጨማሪም በመቅረፀ ድምፅ እንድቀዳ የአንትን/የአንቺን ይሁንታ በትህተና እየጠየኩኝ፤ ይህ የተያዘው ማስታወሻም ሆነ የተቀዳው ድምፅ ለዚህ ጥናት ብቻ በምስጢር የሚያዝና ከዚያ በኋላ የሚቃጠል እንደሚሆን እንዲሁም ከጥናት አድራጊው ውጪ ማንም አንደማያገኘው አረጋግጣለሁ፡፡

የጥናቱ ጥቅም፡- የዚህ ጥናት ተሳታፊ በመሆንህ/በመሆንሽ የተለየ ቀጥተኛ ጥቅም አይሰጥህም/አይሰጥሽም፡፡ ይህ ማለት ግን ጥናቱ ጥቅም የለውም ማለት አይደለም፤ ይልቁንም የጥናቱ ውጤት በመሰል የጤና ሁኔታ ውስጥ ያሉ ሰዎችን የጤና ክብካቤ ለማሻሻል ግብአት የሚሆንና ለበለጠ ስራ የሚረዳ ይሆናል፡፡ከዚህ ባሻገር ቃለ ምልልሳችንን እንደጨረስን ሻይ ቡና የሚኖረን ይሆናል፡፡

የጉዳት ስጋት፡- በዚህ ጥናት መሳተፍ ምንም ዓይነት ተፅዕኖም ሆነ ጉዳት የሌለው ሲሆን ለዚህም የጥናቱ አድራጊ ሀላፊነትና ተጠያቂነቱን ይወስዳል፡፡

እንግዲህ ከላይ ያነሳኋቸውን ሃሳቦች ከግንዛቤ በማስገባት በጥናቱ ስለመሳተፍ የደረስክበትን/የደረስሽበትን ውሳኔ ከዚህ በታች ባለው አጭር ማስታወሻ ስር እንድታመለክትልኝ/እንድታመለክቺልኝ በትህትና እየጠየኩኝ፤ ከዚህ ባለፈ መጠየቅ የምትፈልገው/የምትፈለጊው ነገር ካለ በማልንኛውም ሰዓት ከዚህ በታች በሰፈሩት አድራሻዎች መጠየቅ ይቻላል፡፡ በጣም አመሰግናለሁ!

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ኢሜል nahomsolomon83@gmail.com
በአዲስ አበባ ዩኒቨርሲቲ የሕብረተሰብ ጤና ትምህርት ክፍል

የጥናቱ ተሳታፊዎች የስምምነት ውሳኔ መስጫ ክፍል

እኔ ከዚህ በላይ የተገለፀውን መረጃ አንብቤ/ተነቦልኝ ስምቼ ይህ ጥናት በእኔ ፍቃድ ላይ ብቻ የተመሰረተና በምሰጪር የሚያዝ፤እንዲሁም ምንም ጉዳትም ሆነ የተለየ ጥቅም አንደማይሰጠኝ የተረዳሁ ሲሆን በዚሁ መሰረት በጥናቱ ሥለመሳተፌ ያለምንም ግፊት በራሴው ፈቃድ የሚከተለውን ወስኛለሁ::

1. እኔ በጥናቱ ለመሳተፍ ተስማምቻለሁ

ፊርማ _____
ቀን _____

ቃለ መጠይቁን አድራጊ

እኔ ከዚህ በላይ ያለውን የስምምነት መረጃ ሰጥቼ ስምምነቱን መቀበሌን አረጋግጣለሁ

ስም _____
ፊርማ _____
ቀን _____

<u>የወላጆች/የአሳዳጊዎች የጥናት መረጃ</u>

ጤና ይስጥልኝ! እኔ ናሆም ሰለሞን በአዲስ አበባ ዩኒቨርሲቲ የሕብረተሰብ ጤና የሁለተኛ ዲግሪ ተማሪ ስሆን በአሁን ሰዓት ስለ ኤች አይ ቪ ኤድስና ተያያዥ የጤና ጉዳዮች ጥናት በማድረግ ላይ እገኛለሁ፡፡ ጥናቱ በተለይ ኤች አይ ቪ ከወላጆቻቸው የያዛቸው ወይም ከውልደታቸው ጀምሮ ኤች አይ ቪ ያለባቸውን ወጣቶች የተመለከተ ሲሆን እነዚህ ወጣቶች ስለሚገጥማቸው የጤና ክብካቤ ጉዳይ፤ ስለሚያሳስባቸው ጉዳይ፤ ስለሚገጥማቸው ችግሮችና ፆታዊ ባህሪና ግንኙነት ላይ ያተኮረ ሲሆን በጥቅሉ የህይወታቸውን ልምድ መረዳት ነው፡፡

የጥናቱ ዓላማ፡-ከውልደታቸው ጀምሮ ኤች አይ ቪ ያለባቸውን ወጣቶች የህይወታቸውን ልምድ ማወቅ ሆኖ የጥናቱ ውጤትም የጤናው ክብካቤ የተሻለ ይሆን ዘንድ እና የኤች አይ ቪ ስርጭትን ለመቆጣጠር ለሚደረገው ስራ አጋዥ እንዲሆን ማድረግ ነው፡፡

የጥናቱ ሂደት፡- ጥናቱ ዕድሜያቸው ከ15-24ዓመት ያሉትን የሚያጠቃልል ሲሆን፤ ከሌሎች የእርስዎ ልጅ በዚህ ጥናት የተካተተው/የተካተተችው እንዲሁ በአጋጣሚ እንጂ ምንም የተለየ ትኩረት ተሰጥቶ አይደለም፡፡ ጥናቱ በቃለ ምልልስ ብቻ የሚያልቅ እንጂ ምንም ዓይነት የደምም ሆነ ሌላ ምርመራ አይኖረውም፡፡ ቃለ ምልልሱ ቢያንስ 1ሰዓት ያክል የሚፈጅ ሲሆን ምናልባት የተዘለለ ሀሳብ ቢኖር እንደ እርስዎና ልጅዎ ፈቃድ በሌላ ቀን ተመልሰን ልንነጋገር እንችል ይሆናል፡፡

የጥናት ተሳታፊዎች መብት፡- በጥናቱ ተካፋይ መሆን በእርስዎ እና በልጅዎ ፈቃድ ላይ ብቻ የተመሰረተ ነው፡፡በእርግጥ እርስዎ እንኳን ፈቅደው ልጅዎ ካልፈቀደ በጥናቱ ያለመሳተፍ መብቱ የተጠበቀ ነው፡፡ በቃለ ምልልሱ ወቅት ልጅዎ የፈለገውን/የፈለገችውን ጥያቄ ማንሳት፣ ቃለ ምልልሱን ማቋረጥም ሆነ መመለስ የማይፈልገውን/የማትፈልገውን ሀሳብ መዝለል ይቻላል፡፡

የጥናቱ ምስጢራዊነት፡-ይህ ልጅዎ የሚሰጠኝ/የምትሰጠኝ መረጃ በማንኛውም ሁኔታ ከዚህ ጥናት ውጪ ለሆነ ጉዳይ አይውልም፤ ምስጢራዊነቱም ሁል ጊዜ የተጠበቀ ነው፡፡ልጅዎም በጥናቱ ተካፋይ ሲሆን/ስትሆን ስሙም/ስሟም ሆነ ሌላውን መለያ መግለፅ አይጠበቅም፡፡አይጠበቅብህም/አይጠበቅብሽም፡፡ በቃለ ምልልሳችን ወቅት የሚነሱትን ሃሳቦች ለማስታወስና የበለጠ ለመረዳት ያግዘኝ ዘንድ ማስታወሻ የምይዝ ሲሆን በተጨማሪም በመቅረፀ ድምፅ እንድቀዳ የእርስዎንና የልጅዎን ይሁንታ በትህተና አየጠየኩኝ፤ ይህ የተያዘው ማስታወሻም ሆነ የተቀዳው ድምፅ ለዚህ ጥናት ብቻ በምስጢር የሚያዝና ከዚያ በኋላ የሚቃጠል እንደሚሆን እንዲሁም ከጥናት አድራጊው ውጪ ማንም እንደማያገኘው አረጋግጣለሁ፡፡

የጥናቱ ጥቅም፡- ልጅዎ የዚህ ጥናት ተሳታፊ በመሆኑ/በመሆኗ የተለየ ቀጥተኛ ጥቅም አያገኝም/አታገኝም፡፡ ይህ ማለት ግን ጥናቱ ጥቅም የለውም ማለት አይደለም፤ ይልቁንም የጥናቱ ውጤት በመሰል የጤና ሁኔታ ውስጥ ያሉ ሰዎችን የጤና ክብካቤ ለማሻሻል ግብአት የሚሆንና ለበለጠ ስራ የሚረዳ ይሆናል፡፡ከዚህ ባሻገር ቃለ ምልልሳችንን እንደጨረስን ሻይ ቡና የሚኖረን ይሆናል፡፡

የጉዳት ስጋት፡- የልጅዎ በዚህ ጥናት መሳተፍ ምንም ዓይነት ተፅዕኖም ሆነ ጉዳት የሌለው ሲሆን ለዚህም የጥናቱ አድራጊ ሀላፊነትና ተጠያቂነቱን ይወስዳል፡፡

እንግዲህ ከላይ ያነሳኋቸውን ሃሳቦች ከግንዛቤ በማስገባት የልጅዎን በጥናቱ ስለመሳተፍ የደረሱበትን ውሳኔ ከዚህ በታች ባለው አጭር ማስታወሻ ስር እንድታመለክቱኝ በትህትና እየጠየኩኝ፤ ከዚህ ባለፈ መጠየቅ የሚፈልጉት ነገር ካለ በማንኛውም ሰዓት ከዚህ በታች በሰፈሩት አድራሻዎች መጠየቅ ይቻላል፡፡

በጣም አመሰግናለሁ!

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<u>የወላጆች/የአሳዳጊዎች የስምምነት ውሳኔ መስጫ ክፍል</u>

እኔ ከዚህ በላይ የተገለፀውን መረጃ አንብቤ/ተነቦልኝ ስምቼ ይህ ጥናት በልጄ ፍቃድ ላይ ብቻ የተመሰረተና በምሰጢር የሚያዝ፤እንዲሁም ምንም ጉዳትም ሆነ የተለየ ጥቅም አንደማይሰጥ የተረዳሁ ሲሆን በዚሁ መሰረት ስለልጄ በጥናቱ መሳተፍ ያለምንም ግፊት የሚከተለውን ወስኛለሁ፤ ይህ ማለት ግን እኔ ልጄን አስገድደዋለሁ ማለት አይደለም፤ የልጄ ተሳትፎ በራሱ/በራሷ ፍቃድ ላይ ብቻ የተመሰረተ ይሆናል፡፡

እኔ ልጄ እስከፈቀደ/ች ድረስ በጥናቱ ላይ ይሳተፍ/ትሳተፍ ዘንድ ተስማምቻለሁ

ፊርማ _____

ቀን _____

<u>ቃለ መጠይቁን አድራጊ</u>

እኔ ከዚህ በላይ ያለውን የስምምነት መረጃ ሰጥቼ ስምምነቱን መቀበሌን አረጋግጣለሁ

ስም _____

ፊርማ _____

ቀን _____

Annex-IV; Interview Guide

I- Socio demographic characteristics;-

- Can you tell me about yourself(**prob**:- age, education level, job, marital status, source of income, with whom are you living,
- Can you tell me about your health status(**prob**:- general, HIV status-when you became aware of it, how you knew your status, how long have you been on ART,

II- Supports of youth who acquired HIV perinatally

- Can you tell me any supportive conditions you have experienced? (**prob**:- from families, friends, neighbors, community, school, working areas, health sectors…)
- Any other supportive conditions you had and wish to be done
- With whom you prefer to discuss about your health and related condition? (**prob**:- any example experience…)

III- concerns of youth who acquired HIV perinatally

- What concerns do you have regarding to your health and related things (**prob**:- in relation to families, friends, neighbors, community, school, medias, health sectors…)
- Disclosure issues,(**prob**:- what you think about disclosing HIV status, when, how, where it should be….)
- What do you prefer to be implemented in such area

IV- Challenges of youth who acquired HIV perinatally

- Any challenges you faced (**prob**:- from your health status, families, friends, neighbors, community, school, working areas, Medias, health sectors…)
- **prob**:- Clinical appointment, ART vs school, job, social involvement
- How you cope the challenges (**prob**:- any example experiences….)

V- sexual behavior and relation of youth who acquired HIV perinatally

- What do you know about reproductive system health?
- What do you think about sexual relation (**prob**:- have you ever engaged, how? With whom, what is your future concern regarding it, what should look like your sexual relation, what you wish your sexual partner to be,)
- What do you think is your role in prevention of HIV transmission

VI- any other concerns you want to share me

VII- summarizing the themes

VIII- Thank you for your kind cooperation, I will re visit you based on your willingness for missed or untouched issues if any.

Annex-V; Amharic version of Interview Guide

የመወያያ ነጥቦች/የቃለ ምልልሱ መነሻ ሀሳቦች

1. መግቢያ/ የጥናቱ ተሳታፊዎች ዳራ
   - እድሜ
   - የትምህርት ደረጃ
   - እስኪ ስለኑሮ፣ ስለ ስራ እናውራ
   - እስኪ ስለጤናህስ/ስለጤናሽ እናውራ
   - አጠቃላይ የጤናህ/ሽ ሁኔታ
   - ኤች ኤይ ቪን በተመለከተ፡-መች እንዳለብህ/ሽ አወቅህ/ሽ፣ እንዴትስ አወቅህ/ሽ፣ መድሀኒት መጠቀም ከጀመርክ/ሽ ስንት ጊዜ ሆነህ/ሽ
2. ኤች አይ ቪ ከወላጆቻቸው የያዛቸው ወጣቶች ያሏቸው ደጋፊ ነገሮች
   - እስኪ ያየሀቸው/ያየሻቸው ደጋፊ ነገሮችን ንገረኝ/ንገሪኝ(ለምሳሌ ከቤተሰብ፣ ከትምህርት ቤት፣ ከጎርቤት፣ከማህረሰቡ፣ ከመገናኛ ብዙሀን…..
   - ሌላ ተጨማሪ ከገጠሙህ/ሽ እና እንዲህ ቢሆን የምትለው/የምትዪው…….
   - ከማን ጋር ነው በጤናህ/ሽ ጉዳይ የምተነጋገረው/ሪው….ከዚህ ጋር ተያይዞ የገጠመህ/ሽ ነገር ካለ
3. ኤች አይ ቪ ከወላጆቻቸው የያዛቸው ወጣቶች ያሉባቸው አሳሳቢ ጉዳዮች
   - ከጤናህ/ሽ ጋር በተያያዘ ምን ምን ነገሮች ናቸው የሚያሳስቡህ/ሽ(ለምሳሌ ከቤተሰብ፣ ከትምህርት ቤት፣ ከጎርቤት፣ከማህረሰቡ፣ ከመገናኛ ብዙሀን ጋር በተያያዘ…..
   - የራስህን/ሽን የጤና ሁኔታ ከመግለፅ እንፃር
4. ኤች አይ ቪ ከወላጆቻቸው የያዛቸው ወጣቶች ያሉባቸው ተግዳሮቶች/ፈታኝ ነገሮች
   - የገጠሙህ/ሽ አስቸጋሪ/ፈታኝ ነገሮች (ለምሳሌ ከቤተሰብ፣ ከትምህርት ቤት፣ከሀኪም ቤት፣ ከጎርቤት፣ ከማህረሰቡ፣ ከመገናኛ ብዙሀን ጋር በተያያዘ…..
   - እስኪ ከመድሀኒቱ አና ህክምናው ጋርስ በተያያዘ(ለምሳሌ የሀኪም ቤት ቀጠሮ፣ የመድሀኒት መውሰጃ ሰዓትና ጥምህርት……..
   - አስቸጋሪ/ፈታኝ ነገሮችን እንዴት ነው የምታልፈው/ፊው
5. ኤች አይ ቪ ከወላጆቻቸው የያዛቸው ወጣቶች ያሉባቸው ያላቸው ፆታዊ ባህሪና ፆታዊ ግንኙነት ልምድ
   - ስለ ስነ ተዋልዶ ጤናና ስነ ፆታ የምታውቀውን/የምታውቂውን ነገር ንገረኝ/ንገሪኝ እስኪ
   - ፆታዊ ባህሪና ግንኙነትን በተመለከተ ያለህ/ሽ ሃሳብና ልምድ፣ (ከዚህ በፊት ግንኙት ነበረህ/ነበረሽ፤ ከሆነ እንዴት ነበር፤ ወደ ፊትስ ምን ዓይነት ግንኙነት እንዲኖርህ/ሽ ታስባለህ/ሽ
   - ኤች አይ ቪን ከመከላከል አንፃር ያንተስ/ያንቺስ ድርሻ ምን መሆን አለበት ብለሽ ታስባለህ/ታስቢያለሽ
6. ሌላ ተጨማሪ ማንሳት የምትፈልገው/ጊው ነገር ካለ
7. የተነሱትን ጭብጥ ጉዳዮች በመከለስ ማጠናቀቅ
8. ስለ ቀና ትብብርህ/ሽ በጣም አመሰግናልሁ፡፡ ምናልባት የተረሳ ነገር ካለ እና ፈቃድህ/ሽ ከሆነ ሌላ ጊዜ መልሼ ላናግርህ/ሽ እችላለሁ፡፡

Annex-VI: Lived experiences of perrinatally HIV infected youth; themes, categories and Codes three view