Psychosocial Experiences of Perinatally HIV-Infected Adolescents: The Case of Adolescents in the Social Support Group at Zewditu Memorial Hospital

By:

EDLAWIT WONDIMU

A Thesis Submitted to the School of Social Work

Presented in Partial Fulfillment of the Requirements for the Degree of Master of Social Work (MSW)

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ADDIS ABABA UNIVERSITY

SCHOOL OF SOCIAL WORK

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Approved by Examining Board

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Internal Examiner_____________________ Signature _______ Date___________

External Examiner____________________ Signature ________ Date___________

Abstract

The study explored the psychosocial aspects of perinatally HIV infected adolescents. Qualitative research method was used to explore the psychosocial impacts HIV has on the adolescents in relation to forming their identity and relationship with others. The method was used to explore the different cases using In-depth interview, key informant interview and observation as a data collection method. The study participants are those who use Antiretroviral Therapy service at Zewditu Memorial Hospital. The participants were selected using purposive and snowball sampling. A total of 12 adolescents participated between the age of 16 to 18. In addition, 4 health-care service providers at Zewditu Memorial Hospital and a professional from HAPCO contributed to the findings of the study. Based on the participants' response, the study finding indicated that HIV has a negative effect on the adolescents' emotion. Nonetheless, HIV has not affected their self-concept and self-esteem, meaning to present and future life, essence of spirituality and economic, health and social life. These adolescents used support from their family, friends and a peer-led support group at Zewditu Memorial Hospital. A debatable concept of the effect of HIV/AIDS on their social and dating life and ability to establish courtship has also been raised. Based on the findings, the researcher included advocacy, awareness creation, and recommendations as to how social workers can be involved.

Keywords: *Adolescents, perinatal infection, psychosocial, HIV and AIDS*

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Contents

List of Abbreviations

AIDS: Acquired Immunodeficiency Syndrome

ART: Anti-Retroviral Therapy

FDRE; Federal Democratic Republic of Ethiopia

FGD: Focus Group Discussion

HAART: Highly Active Anti-Retroviral Therapy

HAPCO: HIV/AIDS Prevention and Control Office

HIV: Human Immunodeficiency Virus

NGO: Non-Profitable Organization

PEPFAR: President's Emergency Plan For AIDS Relief

UNAIDS: United Nations Programme on HIV/AIDS

UNICEF: United Nations Children‘s Fund

WHO: World Health Organization

Chapter One: Introduction

1.1 Background of the study

The term mother-to-child transmission is very common, it is where an HIV infected mother transfers the virus from her to the infant in the womb, during birth or through breast feeding. This period between the last weeks of pregnancy to 24 weeks of breast feeding is known as the perinatal period (Stoto & Goldman, 2003). Without the right treatment the risk of HIV/AIDS transferring from the mother to the fetus until the last few weeks of pregnancy is 5%. It increases to 20% during the entire perinatal period. Antiretroviral drugs and antiretroviral therapy are used to reduce the risk (Perinatal Education Programme, 2008).

Implementation of guidelines for counselling, a mother's awareness of her HIV status by testing, and taking medication at the right time to help prevent her child from acquiring the virus while she is pregnant, and ART treatment after the infant is born has brought down the transmission to 1% in Sub-Saharan Africa (Kaplan, 2013). In the case of Ethiopia, the data on eliminating mother-to-child transmission of the virus states that the percentage of pregnant women living with the virus accessing ART medicine has increased from 21% in 2010 to 59% in 2017. But early infant diagnosis has decreased from 40% in 2010 to 38% in 2017 (UNAIDS, 2018).

The advanced healthcare and ART treatment reduce the transfer of the virus from a mother to the child and leads to the survival of these children through adolescence, it provides them the opportunity to mature to young adults. This adolescence stage of life comes with a normal developmental challenge including puberty, sexuality and the desire to be "normal" or like any other individual their age and it gets more complicated with a lifelong disease like HIV (Narasimha, 2013).

Being an HIV positive adolescent comes with different requirements of having to struggle to figure out who they disclose their diagnosis to, the responsibility of taking care of their health and taking their medicine properly without the guidance of an adult. They become more aware of the person they are growing into and struggle to have better self-identity. In addition, the older they get the thought they have of having to be in an intimate relationship, expressing oneself sexually, and if gets further thought of one day being a parent have a massive toll on them (Close & Rigamonti, 2010).

Between 25% and 30% of children who acquire HIV from their mothers die before their first birthday. Most of them will have acquired HIV in utero or around the time of birth. More than half (50-60% of the children) develop symptoms early in life and, in the absence of timely diagnosis and effective treatment, die by the time they are two years old. In a study of almost 3500 children enrolled in seven perinatal trials in sub-Saharan Africa, for example, 35% of HIV-infected children had died by age one year, and 53% had died before they reached the age of two years. Without effective prevention measures, the risk of HIV transmission from an HIV infected mother to her child, before or during the child's birth, is 15–25%. If the mother breastfeeds her newborn until 18– 24 months, that risk increases to 30-45%. This research aims to grasp the psychosocial outcomes of the virus on these adolescents in terms of feelings, thoughts, beliefs/spirituality, attitude they have towards their diagnosis, living condition, relationships, education, vulnerability, stigma and discrimination.

1.2 Statement of the Problem

According to a study in 1998, the probability of a child being infected by the virus from the mother is about 25% (Thompson, Aronstein and Shelby, 1998). Of all these infants, about half of them develop severe illness; the first year they are born which is caused by the virus and may lead to the death of the child. The range of infection while breast feeding is 14-15% higher than it is during pregnancy and delivery.

As access to services for preventing the mother-to-child transmission of HIV has increased, the total number of children being born with HIV has decreased. An estimated 370

000 [230 000–510 000] children were newly infected with HIV in 2009 (UNAIDS,2010). An estimated number of 370,000 children were newly infected with HIV in 2009, the number had decreased to 160,000 in 2018 (UNAIDS,2019). The beginning of advanced healthcare and ART services reduces the number of mortalities among children living with the virus, leading to them surviving through adolescence.

Mavhu, Berwick, Chiraw, Makamba, Copas, Dirawo, et al. (2013) on their study in Zimbabwe stated that these children while growing up are faced with frequent hospitalization, loss of one or both parents, less school attendance, delayed puberty and intellectual impairment and many more issues that come with the disease. With the advanced medical technology, HIV is no longer terminal but a chronic illness. Close and Rigamonti (2010), stated that of the main characteristics experienced by children with chronic illnesses or conditions, children with HIV infection may experience limitation of developmentally appropriate functioning, dependency on medication, need for more medical care than is normal for their age, disfigurement resulting from certain opportunistic infections or severe wasting accompanying progressive disease (p. 296)

For HIV positive children who live through the age of adolescence with the virus have more complicated pubertal development, coping with their own possible death, stigma, emotional and behavioral problems due to the complexity of their illness and treatment (Narasimha, 2013). This statement is backed up by a study in Madrid, it states the emotional and behavioral problems of adolescents that are HIV positive reported to be 24.5% (Medin G, et al, 2016).

Adolescents are important sections of population in a country with pivotal role for future development. They need all the special care and attention. This age is the time where psychosocial effects are magnified, which gets worse when they are born with a lifelong disease which has been transmitted from their parents. Thompson, Aronstein and Shelby

(1998), stated how people living with HIV/AIDS compare themselves against uninfected peers. Taking pills every single day and having to take extra care for themselves unlike their friends who they consider "normal" or "healthy" might be emotionally damaging.

Researches on HIV and adolescence emphasized the challenges associated to disclosure of their status to others around them, stigma and discrimination, risk of depression and isolation while requiring the importance of social support. For example Ramaiya, Sullivan, Donnell, Cunningham, Shayo, Mmbaga and Dow (2016), reported from their study in Tanzania that some of the main challenges faced by HIV positive adolescents includes the acceptance of their HIV status especially if they are told late, loss of parents leading to financial stability, stigma and HIV related bullying, and the negative effect disclosure has led them to question their self-worth and identity.

Among the adolescence period, the age from 16 to 18 year is the time where most of them have gone through physical changes due to puberty. This is the latest age category before someone legally becomes an adult. As adolescents grow, they start relationships outside their school friends and family. It is also the age where they learn to explore their emerging sexuality and new intimate relationship: which brings up the idea of disclosing their HIV status, leading to the above-mentioned challenges associated to self-esteem, self-worth and identity. The studies that have been conducted in Ethiopia in relation to perinatal HIV infection focus on children under the age of 15 and their caregivers (Zerubabel Elias, 2014; Roman Negewo Desta, 2014; Jemila Abdellah, 2009; Gashaw Aragie, 2015; Abera Rundasa, 2015; Tigist Argaw, Etsegenet Gedlu, 2016).

Studies conducted in Zimbabwe stressed the importance of psychosocial support for the adolescents (Mavhu, et al, 2013), Psychosocial and mental health context of the disease in Tanzania of how their wellbeing is affected with concepts like death and bereavement, (Ramaiya, Sullivan, Donnell, Cunningham, Shayo, Mmbaga and Dow, 2016), and Disclosure, treatment adherence, and behavioral profile in Madrid stressed the effect of disclosure from parent's or health service providers (Medin G. et al, 2016) The aforementioned studies focused on the effects of the virus on different psychosocial aspects in relation to stigma and discrimination, and disclosing diagnosis to others, missing classes and the effect it has on their education, risk of depression, anxiety and related problems.

However, there has not been an in-depth study on perinatally HIV infected adolescents related to dating and intimacy in Ethiopian context, concept of self-esteem and identity, their outlook on life and their future and spirituality as a support system. The proposed study plans to explore the life experiences adolescents living with HIV in the areas of courtship, self-concept and identity, spirituality, their expression or giving meaning to the present life and the future all of which are lightly explored or not at all by previous researches.

1.3 Objectives

1.3.1 General Objective

The general objective of the proposed study is to explore and analyze the psychosocial status of adolescents living with HIV in the aspects of self-concept and self-esteem, dating/courtship, meaning/expression of present life and the future, and spirituality.

1.3.2 Specific Objectives

The specific objectives are to:

- Explore how adolescents describe their self-concept and self esteem
- Examine the experiences (challenges and opportunities) of adolescents with HIV in their interest of dating or establishing courtship
- Understand how adolescents with HIV express or give meaning to their present life and the future
- Assess the health and economic effects of their HIV status

- Explore their spirituality and how it affects other aspects of their life

1.4 Research questions

- How do perinatally HIV infected adolescents describe their self-concept and self-esteem?
- What are the challenges and opportunities of adolescents with HIV in their interest in dating or establishing courtship?
- How do adolescents with HIV express or give meaning to their present and future life?
- What are the health and economic effects of their HIV status?
- What is the essence of spirituality in adolescents with HIV? And how it affects other aspects of their living?

1.5 Definitions of terms and concepts

1.5.1 Conceptual definition

Acquired immunodeficiency syndrome (AIDS): is the disease of the immune system due to infection with HIV, it is the most advanced stage of HIV infection (U.S. Department of Health and Human Services, 2018, p.2).

Adolescents: are individuals between the age of 10 to 19 going through a transition involving biological, psychological and social dimensional changes (UNICEF, 2006, p. 1).

Antiretroviral Therapy (ART): Antiretroviral therapy is the daily use of a combination of HIV medicines (called an HIV regimen) to treat HIV infection. A person’s initial HIV regimen generally includes three antiretroviral (ARV) drugs from at least two different HIV drug classes (U.S. Department of Health and Human Services, 2018, p.10).

Caregiver: a caregiver is someone who gives attention to the needs of others, especially those who are not able to look after themselves adequately (Hermans & Smith, 2012, p.1)

Courtship –to seek the affections of specially to seek a pledge of marriage from someone (Niehuis, 2008, p. 1)

Dating - an appointment or a series of appointments with a person one is socially, romantically, or sexually interested in (Niehuis, 2008, p.1).

Discrimination: discrimination means to exclude a person from the full enjoyment of their social, civic, economic, political or cultural rights and freedoms (Lippert, 2013, p.3).

Perinatal transmission: When a mother with HIV passes the virus to her infant during pregnancy, labor and delivery, or breastfeeding (through breast milk) (UNICEF, 2006, p.133).

Self-Esteem: defined broadly as the manner in which individuals perceive or evaluate themselves, is considered to be an important variable in contributing to emotional and behavioral adjustment, academic attainment and other educationally significant outcomes (Miller and Moran, 2012, p.40).

Self-identity: self-identity is defined as the traits and characteristics, social relations, roles, and social group memberships that define who one is. Identities can be focused on the past-what used to be true of one, the present-what is true of one now, or the future-the person one expects or wishes to become, the person one feels obligated to try to become, or the person one fears one may become (Rodrigues, Stobäus & Mosquera, 2016, p.1120).

Spirituality: Is the core of person's involvement in one's relationship with God or a higher power, it is a possession of human beings, enabling self-awareness, heightened consciousness and providing the strength to exceed the usual self (Dayson, Cobb & Forman, 1997, p. 1184).

Stigma: Stigma is a perceived negative attribute that causes someone to devalue or think less of the whole person (Kang, 2013, p. 393)

Support group: support group is a collection of people with common concerns and needs that can share their experiences and help each other through difficult periods, and thereby achieve better health and well-being of all members. Allows people to meet their needs, heal themselves and assist others is doing the same in an understanding and caring environment (Sweetland, Lazarus, Freeman & Saloner, 2005, p. 1)

1.5.2 Operational Definition

Adolescents: in this study refers to a person between the age of 16-18.

Care giver: is a member of a household or extended family who is giving social, economic, and/or psychological care and support and/or personal care and assistance to the adolescents.

Dating: the act of building a relationship with the opposite sex for the purpose of having a romantic bond.

Spirituality: the belief one has about the source of strength and support to cope with their illness.

Self-concept: the understanding one has of the behavior, attitudes and strength of herself/himself.

Support group: a collection of perinatally HIV infected adolescents that provide each other non-professional help and share coping mechanisms.

1.6 Delimitation of the study

The study was conducted among a group of adolescents living with HIV receiving ART services but also who are active participants in the weekly support group (peer-led group) service provided at Zewditu Memorial Hospital. The study limited itself to include adolescents at the age of 16, 17 and 18 years. This age category is considered as a late adolescents age during which individuals give more emphasis to self-concept, self-esteem, dating, planning the present and the future and is a heated stage to decide spirituality as a support and strengthener. The target are the ones attending weekly support group meeting.

1.7 Significance of the study

The study provides a better understanding about the effects HIV has on adolescents' life in the areas of self-concept, self-esteem, dating and establishing courtship, meaning to present and future life and spirituality. Although numerous studies have been conducted to understand the impacts of the infection on the infants who were either born positive or get infected after birth, the impact on those who survived and grown up to become adolescents has not been adequately studied. Thus, this study will bring knowledge of this specific age group and provide insight about the effects of the infection on the unexplored areas of their life.

Chapter Two: Literature Review

Introduction

This chapter presents a review of literatures relevant to the study. It draws on the literature from around the globe and countries in Africa where HIV/AIDS prevalence is high. The chapter has sections that briefly state the definition and description of mother-to-child HIV transmission, adolescence and their psychosocial wellbeing, researches conducted on disclosure, stigma, mental health, and coping strategies. It also highlights a few concepts that need further study including self-esteem, self-worth and identity, dating and intimacy, and spirituality.

2.1 Mother-To-Child HIV Transmission

Mother-to-child transmission of HIV takes place during what is referred to as the perinatal period; which is the last few weeks of pregnancy, labor, and delivery or breastfeeding (Close & Rigamonti, 2005). The level of HIV crossing the placenta from the mother to the fetus during the perinatal period without the right treatment (ART prophylaxis) is about 20%. The 5% of this transmission is during pregnancy, but it increases to 15% after birth during breastfeeding (Perinatal Education Programme, 2008). With no intervention, between 20% and 50% of infants born to HIV-infected mothers will themselves become infected with HIV. With an estimated risk of 5%-10% during pregnancy, 10%-20% during labor and delivery, and 5%-20% during breastfeeding (Tolle & Dewey, 2005).

After the introduction of Highly Active Antiretroviral Therapy (HAART) the number of new infections had been decreasing from year to year worldwide. UNAIDS data in 2010 stated the decreasing number of children who contracted the disease from their mother has decreased from 500,000 in 2001 to 370,000 in 2009. Which also led to a 19% decrease in AIDS-related deaths globally among children from 2004 to 2009 (UNAIDS, 2010).

In Ethiopia, the percentage of pregnant women living with HIV accessing antiretroviral medicines has increased from 21% to 59% and early infant diagnosis has decreased from 40% to 38% in the year 2010 to 2017 (UNAIDS, 2018). The number has shown a drastic increase of pregnant women living with HIV on ART from 59% in 2017 to 92% in 2019. And the number of early infant diagnosis has increased from 52.5% in 2010 to 60.8% in 2018 (UNAIDS, 2019).

The above data provides an understanding of the reduced number of mortalities in children born with the virus. Since the year 2004, there has been an increase in the supply of pediatric ART, which provides these children born with the disease a fighting chance to grow into adolescents (Lowenthal, Bakeera-Kitaka, Marukutira, Chapman, Goldrath & Ferrand, 2014). The following part of the literature review will discuss how perinatally HIV infected adolescents are affected by important aspects of the HIV/AIDS pandemic including disclosure, stigma, and mental health issues from psychological wellbeing point of view.

2.2 Adolescence and Psychosocial Wellbeing

2.2.1 Understanding Adolescence

Adolescence is a transitional phase from childhood to adulthood through physical, emotional and cognitive growth and development. According to a handbook on counseling and psychosocial care for children and adolescents living with and affected by HIV (Nasaba, Rosemary, Tindyebwa, Musiime, Iriso, Ingabire, Nansera, Etima-Kizito, Kasule & Duffy, 2018), a normal growth development for adolescents between the age of 14 to 18 includes physical development into the last stages of adulthood, emotionally: mood swings occur but also severely influenced by peers, and the search for identity and same-sex friendships becomes more significant. When it comes to their cognitive development, it is this stage that they ignore consequences but pursue pleasure.

2.2.2 Psychosocial Wellbeing

The Republic of South Africa Department of Health defines psychosocial well-being as:

> Psychosocial well-being refers to the social and emotional well-being of an individual, and the ability to fulfill his/her potential as a human being. It includes many areas of the individual's life: the psychological aspects, including, emotional, cognitive, mental health and spiritual issues; while the social aspects refer to relationships with others, the environment, and society. These aspects of well-being also influence physical health, and how the patient engages in his/her own treatment, adherence or disclosure issues (2019, p. 10)

The psychosocial wellbeing of adolescents can be affected by the way they were nurtured and exposed to the environment, type of home and parents, economic status, loving and caring atmosphere (Ajidahun, 2011). In agreement with this finding, a study conducted in the psychosocial effects of HIV in perinatally infected adolescents found that the participants were detached from their families which in result caused them to have trouble in forming secure relationships (Mavangira & Raniga, 2015). These adolescents may live with their extended family but may not feel like they are a part of the adopted home. This, in turn, leads to self-isolation and feeling unloved (Armstrong, Iorpenda, Caswell & Kihara, 2017).

Adolescents who acquired HIV through perinatal infection have the following characters:

> Experience delayed puberty, stunting and cognitive development, be unaware of their HIV status, and will need to be supported to understand the elements of positive living and disclosing to others, have parents and caregivers who are aware and usually engaged in care, have lost one or both parents, with variable support from other family members or caregivers. They may have been moved around frequently or be in institutionalized care,

> struggle against caregivers and health care providers to establish independence , have long-term experience of ART with side effects, and they may experience treatment fatigue, be on second- or third-line treatment due to treatment failure, have a history of illness and frequently attend hospital or clinics, feel concerned about a normal sex life, having a family and the future, hold views of HIV shaped by family and service providers (Armstrong, Iorpenda, Caswell & Kihara, 2017, p 7).

2.3 Studies Conducted on Perinatally HIV Infected Adolescents

2.3.1 Disclosure

The introduction of pediatric ART has led to the infected children growing and surpassing the immediate threat of death which resulted in high level of life expectancy: but also brought the agenda of informing their HIV status which is a complicated issue with emotional involvement of the parent/caregiver and healthcare provider.

A comprehensive literature review by WHO to find evidence to support disclosure of children and adolescents' HIV status provided the health benefit of reduced risk of death, the lessened effect of emotional and psychological problems from the disclosure and how these effects have decreased through time with the help of counselling. This is more of an adjustment process by children, caregivers and the community to the diagnosis and the challenges it carries (WHO, 2011) This agrees with a qualitative study by Gashaw Aragie (2015) of children living with HIV/AIDS in Kolfe Keraniyo Sub-City; which in his finding stressed the importance of disclosure to have better medication adherence, understand the reason behind taking medication daily and going to the hospital for checkups constantly and accept their status. Jemilah Abdellah (2009), on her study *Disclosing HIV positive status to children: Challenges and experiences of parents and guardians of HIV positive children,* revealed that guardian preferred partial disclosure; having to tell their children that they are sick and the only way to keep living is to take their medication right but without having to tell them the name of their diagnosis.

A study conducted in Harare, Zimbabwe on adolescents between the age of 16-20 and healthcare workers on their experience of disclosure found the following result. While healthcare workers encourage home-based disclosure both parents/caregivers and the adolescents themselves preferred the clinical setting. The adolescents also chose to get psychosocial support from the group at the clinic with those they shared experience with. The study emphasized the importance of the adolescent's preference in the HIV disclosure process and role of per support groups in clinical setting to cope with the effects their diagnosis leads to. This finding of caregivers' preference of the disclosure status has also been supported by a study conducted on the disclosure of HIV status among children and adolescents attending pediatric infectious disease clinic at Tikur Anbessa Specialized Teaching Hospital in Addis Ababa, in this study 52.3% of the caregivers preferred a health center caregiver providing the HIV status disclosure (Tigist Argaw & Etsegenet Gedlu, 2016).

Although disclosure is associated with improved adherence to medication and follow-ups at hospitals and clinics, there are significant number of children and adolescents that have been perinatally infected receiving treatment without being fully informed of their diagnosis. Several researches have been done in relation to disclosure both in Ethiopia and elsewhere including prevalence of disclosure of HIV positive status and its predictors among children and adolescents with HIV infection attending the pediatric infectious disease clinic at Tikur Anbessa Specialized Teaching Hospital (Tigist Argaw & Etsegenet Gedlu, 2016); the study included 233 HIV positive children between the age of 6 to 18, only 32% of them knew their diagnosis. And of these, more than half of the disclosure process was carried out by healthcare providers. The finding led to the conclusion that the disclosure barrier in healthcare providers needs to be addressed and education strategies should be considered. In agreement with this is a study by Shitahun Fentie (2017), who explored the experience of the healthcare providers, they suggested the improvement of training and availability of guidelines to alleviate the discrepancies.

Tadesse Birkneh Tilahun, Byron, Foster, Yifru Berhan (2015) in their study *Cross sectional characterization of factors associated with pediatric HIV status disclosure in Southern Ethiopia*; of the 177 participants only 33.3% of them were aware of their status. And that the prevalence of disclosure of those above the age of 10 increases. This finding was supported by another study done by Roman Negewo (2014), entitled *Assessment of magnitude and factors that affect care givers' disclosure of HIV diagnosis to their HIV infected children in Addis Ababa.* Of the 372 participants between the age of 6 to 15, only 29.8% of them were aware of their diagnosis and that their caregivers preferred to disclose their status after the age of 10. While it was revealed in her study that the low prevalence of disclosure is due to fear of stigma and discrimination.

A qualitative study on perinatally-infected adolescents in Zimbabwe (Kidial, Mupambireyi, Cluver, Ndhlovu, Borok & Ferrand, 2014), did an in-depth interview with 31 adolescents. These adolescents preferred the disclosure process to be carried out in clinical setting to have access to accurate information from healthcare providers. And that after disclosure, they found ease in understanding the sickness better from their peers during peer support group meetings. The study highlighted the important role of support group in assessing the disclosure process.

The concept of disclosure does not only concern caregivers and healthcare service providers but also the adolescents making decisions to whom they disclose their status to. Fear of stigma and discrimination may deter them from disclosing their status. Disclosure to family members who do not know of their status, friends and sexual partners depends on the consequences one anticipates resulting from the disclosure. Disclosure occurs to those who pose little risk and no harm to them. And the study *Depression, internalized HIV stigma and HIV disclosure* (Okello, Wagner, Ghosh-Dastidar, Garnett, Akena, Nakasujja and Musisi 2015) concluded from the finding the effect stigma has on HIV disclosure decision making. Adolescents are often selective about when and to whom they tell their status as a form of stigma management and isolation (Close & Rigamonti, 2010).

2.3.2 Stigma and Discrimination

Stigma is HIV/AIDS-related process of devaluation of people either living with or associated with HIV and AIDS. While discrimination "occurs when a distinction is made to a person that results in him or her being treated unfairly and unjustly based on belonging or being perceived to belong to a group" (International Center for Research on Women, 2006, p. 2). Stigma can also occur when a person experiences self-stigmatization where he or she internalizes the negative responses and reactions of others. Stigma and discrimination can impact the way family, friends, neighbors and the entire community interacts with these segments of the population and also distress the struggle to fight against the epidemic (Harper , Lemos & Hosek , 2014).

Stigmatization does not only occur from the society but also in the family setting by caregiver and other extended family members. The act of stigmatization includes separation of household utensils, unequal distribution of finance and emotional support. The respondents also explained that some of these acts occurred due to lack of understanding of how the disease is transmitted. 70% percent of the participants from a study conducted by Ramaiya, Sullivan, O' Donnell, Cunningham, Shavo, Mmbaga & Dow (2016) experienced stigma on family, peer and community level. They expressed their fear of ridicule, gossip and social isolation.

A study in Botswana found out that stigma occurs due to misconception of how the disease is acquired or transmitted. Those with wrong beliefs of how it can be transmitted tend to stigmatize people living with HIV more than those who know how it is transmitted (Letamo, 2004). A data by UNAIDS reveals that more than half the population in Ethiopia was reported to have stigmatizing attitude and 42% of the population believed that children living with HIV should not be allowed to attend school with other children (UNAIDS, 2019).

2.3.3 HIV Positive Adolescents and Mental Health

According to WHO (2012), there is an interdependence between mental health and HIV/AIDS. HIV can cause several psychological conditions due to circumstances that surround the disease and HIV-related neurological changes. Given the range of psychosocial challenges mentioned above and more, HIV positive adolescents are particularly in a vulnerable position to acquire mental health problems. A study in Tanzania revealed the psychosocial challenges that lead to mental health problem. These include: acceptance of HIV status, with 54% of them feeling "different" and powerless, loss of parent(s) leading to financial instability, maltreatment by current caregivers, and lack of unique parent-child bond, domestic violent acts of psychical beating and emotional abuse, financial distress leading to periodic gaps in medication adherence and enrolling or continuing school (Ramaiya, et al. 2016). These adolescents grow up with the identity of being medically dependent, which leads to high prevalence of anxiety, depression, suicidal thoughts and conduct disorder. Many of their psychological problems occur due to high self-directed stigma, shame and anger (Vreeman, McCoy & Lee S., 2017).

A study in Harare, Zimbabwe to explore the experience and manifestation of depression in adolescents living with HIV found the following as the main contributing factors causing depression: being different from others, learning of their HIV status, isolation and rejection, loss and grief of parents, low self-worth, lack of protection and inflicted abuse and fear of the future (Willis, Mayhu, Worgin, Mutsinze & Kagee, 2018). A quantitative study of 103 HIV positive adolescents in Choma, Zimbabwe found that 85.4% (by self-rated

Strengths and Difficulty Questionnaire) had mental health problems. These adolescents admitted to feeling agitated, depressed, aggressive, need to harm oneself, low ability to concentrate and think, and misuse substance (Lyambai & Mwape, 2018).

2.3.4 Coping Mechanisms to Mitigate HIV/AIDS Impacts

From the different materials that have been reviewed, the strategies and mechanism these adolescents used to cope with the impacts of the disease included peer-led support groups, supportive care givers, education assistance and skills training for future employment. These played a role in improving their sense of worth, the fact that they belong to a group that had the same experiences as them reduced their sense of isolation and rejection. In addition, it can help fill the gap lacked by the support from caregivers and peers (Willis, et al,2018).

Finding comfort knowing that they are not the only ones living with the disease, better medication adherence for the fact that it reduces risk of death, avoiding worry and finding ways to distract themselves from negative thoughts, to utilize both emotional and practical support and religiosity has been found as the coping mechanism for perinatally infected HIV positive adolescents living in Uganda (Mutumba, Bauermeister, Musiime, Byaruhanga, Francis, Snow & Tsai, 2015). Another quantitative study in Nigeria has found seeking social support, religion and mental disengagement as a coping mechanism, which in turn helps with their adherence to medication and their ability to handle long-term consequences of risky behavior (Folayan, Cáceres, Sam-Agudu, Odetoyinbo, Stockman & Harrison, 2017).

2.4 Concepts that need Further Studying

2.4.1 Self-esteem, Self-worth, and Identity

An adolescent by developing a sense of identity is trying to answer the question “who am I?” and “where do I belong?”. A personal identity is a sense of oneself, it encompasses a person's perception of the group they belong to and the values they have (Sumner, 2020). Adolescents also have a higher need for approval and acceptance from their peers and others around them (Feldman, 2003). In addition, Sumner (2020) states that identity formation is something that changes through different experiences. With the knowledge of one's pending mortality, adolescents may become concerned about future aspiration and goals, which in turn affects the process of identity formation (Hosek, Harper and Robinson, 2002).

An adolescent's ability to identify oneself, the level of self-worth and self-esteem can be affected by the type of disclosure, the strength of support, the level of education, the act of stigma and discrimination they have faced, types of peers they spend their time with and many more. Their self-worth is affected by the type of relationship they have with their peers and family members or caregivers (Willis, et al 2018). A cross sectional study of 195 participants including 65 perinatally infected adolescents between the age of 11 and 18 revealed that these adolescents are at higher level of developing low level of self-esteem. This was related to the negative consequence of dealing with the disease, which also led to depression and social isolation. (Louthrenoo, Oberdorfer B., Aurpibul L. & Sirisanthana V., 2018).

2.4.2 Dating and Intimacy

Dating is not only a simple part of courtship that leads to marriage, it provides a way to build intimacy. An article titled "*I definitely want grandbabies": Caregivers of Adolescents with Perinatally-Acquired HIV Reflect on Dating and Childbearing.* The participants believed that their children would make good parents and also the adolescents themselves indicated that one day they would want a child. These parents were fully aware of their children's dating status, made sure they protected themselves and had conversations about their sex life openly (Fair, Cynthia & Albright, Jamie & Clark, Devon & Houpt, Bethany, 2016).

Hosek, Harper and Robinson (2002), found a participant that changed her thought of marriage and having a baby after she found out that she was HIV positive. Having to disclose her status to every person that she meets was a burden to her and hard to deal with. Another study in revealed that some of the participants had never disclosed to a romantic partner, but carefully managed intimacy due to their anticipation of eventual disclosure, rejection and other HIV-related issues (Fair, Cynthia & Albright, Jamie, 2012). A study in Côte d'Ivoire by of the age 13-17 participants of the study revealed that some were worried whether they could ever marry or have children (Dago-Akribi & Adjoua, 2004).

2.4.3 Spirituality

Spirituality is one of many ways' teens with HIV and their families cope with the burdens of HIV. Facing different stressors and challenges, these adolescents state their belief in a higher power as a coping mechanism. A qualitative study in Tanzania found that from the 24 participants of the study, 6 of them believed in the existence of a higher power for support and strength (Ramaiya, Sullivan, O' Donnell, Cunningham, Shavo, Mmbaga & Dow, 2016). Similarly, a study of spirituality and religion in patients with HIV/AIDS found that patients with a spiritual and religious belief had greater optimism, greater self-esteem, greater life satisfaction, and they drank less alcohol (Cotton, Sian, Puchalski, Sherman, Mrus, Peterman, Feinberg, Pargament, Justice, Leonard & Tsevat, 2006). A qualitative study by Jemila Abdelah (2009), asked what the participants health seeking behavior was, some said that they chose praying before going to hospitals. Another study by Liyu Wogayehu (2015), found spirituality as one of the protective factors for HIV positive adolescents living in the center she did her study at. Despite the above studies, there seems to be a limitation in materials that reveal the belief these adolescents have with a higher power, regardless of their religion.

A qualitative study done in Thailand on 22 adolescents who are living with HIV revealed that spirituality has helped the adolescents to feel responsible towards others, to care for oneself, keep their focus on life's purpose, maintain hope for cure and understand the disease and accept the truth about life (Balthip, McSherry & Nilmanat, 2017). A study on 80 adolescents and their family on their spiritual wellbeing concluded that integrating spiritual practice into HIV services may diminish behaviors associated with the transmission of HIV to others, while improving the quality of life and physical health of HIV infected youth from the finding (Lyon, Garvie, Jianping H., Malow, McCarter & D' Angelo, 2014).

Chapter 3: Research Methods

3.1 Researcher's Stance

A researcher's stance shows how a researcher sees the world. It is based on this world view that the research design is chosen. The researcher's stance on reality is that it is subjective and can be constructed through experience. Creswell (2007), better defines social constructivist to mean that the researcher depends on the participants' view of a situation. In this study, the meaning the participants give to HIV and the impacts it has on their lives is expected to be explained from their point of view and perspective. While there have been different studies and articles on the specific group being studied, the researcher finds it important to let the study participants explain their experience with their own words and expressions.

3.2 Study Setting

Zewditu Memorial Hospital is found in Addis Ababa, Ethiopia. Currently the Hospital is operated by Addis Ababa Health Bureau. It is the leading hospital in ART and the largest HIV clinic in Ethiopia. The ART center at present gives services for more than 6,000 outpatients. A part of the beneficiaries of the ART services are the adolescents who get treatment and attend the weekly support group session led and coordinated by doctors, nurses, clinical psychologists and other professionals at the center. There are more than 130 outpatient service users who attend the 10 to 19-year-old support group being held at the center every Saturday.

The support group is a weekly meeting for perinatally infected adolescents. Since there is a large number of adolescents, it is not easy to accommodate all of them at once. Therefore, they were split into a group of four. Each group attends the meeting once a month. They have discussions about their status and other points they need more information on. There are days where they get to interact with those who used to be a part of the group and are now living their own lives. These individuals get to explain to the adolescents how their status has not affected their future. After the meetings, they get to have lunch at the center, and they are given transport allowance. The program lasts from 9 a.m. to 1 p.m.

The support group currently gives service to 160 adolescents who have been disclosed and joined the program voluntarily. The program is coordinated by the Medical Doctor Aster Shewa Amare, who has been facilitating different programs in relation to HIV for more than 15 years. The program is funded by PEPFAR (President's Emergency Plan For AIDS Relief). PEPRAF offers donation for trainings, manpower and other needs of those suffering with the disease. Different professionals at the center gather twice a month to plan the contents of the weekly support group meeting. In addition, the adolescents have chosen two group leaders, who interact and collaborate with the professionals to coordinate and plan the contents of the weekly sessions.

3.3 Research Design

The general objective of this study was to explore the psychosocial effects HIV has on perinatally infected adolescents. Given the fact that this topic is the least studied area in the country, exploratory research is selected. According to Williams, (2003) exploratory research is usually conducted when there are few or no earlier studies to which references can be made for information**.**

This study employed a qualitative method. Qualitative research seeks to understand a given research problem or topic from the perspectives of the local population; it involves and helps a researcher to gain a rich and complex understanding of a specific social context (Mack, Song, Macqueen, Guest & Namey, 2005**)**. Qualitative method is explained as an approach that helps us explore and understand a meaning participant give to the problem (Creswell, 2014). The primary focus is to help gain meaning attached to a social phenomenon by the study participant (Whittaker, 2009). The Following study tries to identify the meaning adolescents give to self-esteem, present and future life, dating and courtship, spirituality and other aspects of their life HIV affects.

3.4 Case Study Approach

This study proceeded with a constructivist worldview making a critical case study as its core strategy. Case study is selected among other qualitative research methods because it is an approach that provides a way to explore a real life with an in-depth data collection (Neuman, 2007). A case study is an appropriate study approach for that it gives a wide opportunity to explore the distinctive and multifaceted experience of the targeted population of this study. It helps develop an in-depth understanding of a single case or explore an issue or problem using the case as a specific illustration (Creswell, 2013). Considering the time allotted to finalize this research, the study is a cross-sectional study. It is where the data is collected at one point in time also known as a snapshot approach (Neuman, 2007).

3.5 Sampling Technique

Participants were selected using non-probability sampling, with purposive and snowball sampling. Whittaker (2009) defines purposive sampling (sometimes known as judgmental sampling) as where a researcher gets to select participants that, in the researcher's judgement, has the information needed for the research. Snowball (sometimes called network, chain, referral, reputational) sampling is another technique used to select participants in small number. Once a participant is chosen or selected, the researcher asks them to recommend another person who could participate in the study and is willing to. One of the most appropriate situations, as Neuman (2007) lists, when to use purposive sampling is to investigate deeply and identify a specific type of case. Purposive sampling was used when the support group coordinator selected participants based on the inclusion criteria. Once the researcher found 4 participants, they recommended someone they thought would fit the selection criteria.

3.6 Participant Selection Criteria

The researcher in this study did not know the participants as much as the health care service providers and those who coordinate the support group, they were the ones to help select those who participated in the study. The following were used as a selection criterion for participants:

- Have been infected by the virus from their mothers
- Are between the age of 16 to 18
- Use the ART service at Zewditu Memorial Hospital for more than three years, that the health care givers are familiar with him/her
- Participate in the weekly support group
- Have been aware of their diagnosis for at least three years and are familiar with it
- Willingness to take a part in the study

3.7 Participants

In qualitative study, even though there isn't a specific number given as a sample it is suggested the sample to be smaller because an in depth and detailed study is needed (Mile & Huberman, 1994). Since there needs to be an in-depth understanding of each of the cases, it is suggested that the number of participants being studied won't be more than four or five (Neuman, 2007). Theoretical saturation must be considered while using a purposive sampling, it is the point where there is no longer a new insight to be brought in as a data (Mack et al, 2005). Accordingly, Creswell (2009) suggests that data saturation is commonly achieved within five to six homogeneous respondents during case study. Considering the higher possibility of respondents' homogeneity, 8 adolescents of four boys and four girls participated in the interview and observation.

3.8 Data Collection Method

The use of wide data collection techniques while conducting qualitative research is preferred rather than relying on a single data sources (Creswell, 2007). Three types of data collection techniques were to be used for this study two types of interviews (in-depth interview and key informant interview of professionals working at the ART center), focus group discussion and observation.

3.9 Data Collection Instrument Development

The researcher developed the data collection instruments to match the topics that need to be covered. These questions are open-ended, general, and focused on understanding the central phenomenon in the study. Each research question was followed with a number of probing questions for the in-depth interview. Questions on the FGD guide and key informant interview were also developed based on the topics that are expected to be vital to the study. The same method was used for the observation checklist. Once the proposal was approved, the In-depth interview and key informant interview questions were translated to Amharic.

In-depth Interview:

The study employed an open ended, semi-structured interview questions. The rationale for selecting this technique was to help collect detailed information in relation to their experience, emotions, thoughts and understanding of HIV and its impact. The study used semi standardized interview with an open-ended question to understand the issue from the participant's perspective (See Annex I). Besides, as Creswel (2007) stated open ended questions better allow the researcher to listen the perspective of participants than the question from closed ended one. An in-depth interview was conducted with 6 girls and 6 boys.

Observation

Observation is a qualitative research method in which the researcher not only observes the research participants, but also actively engages in the activities (including the weekly support group meeting) of the research participants. This requires the researcher to become integrated into the participants' natural setting while also taking objective notes about what goes on in that specific setting (Neuman, 2007). The researcher gets to see things that are familiar to the participant but does not consider it important enough to mention (Dawson, 2007). The research was to apply a disclosed participant observation, where the participant is aware of the researcher observing them while they are in their natural setting including their schools, homes and the hospital. The participants were told that they will be observed in different settings at the beginning of the study but were not told where and when to avoid the artificial behavior they would display when they know they are being observed. The above plan was before COVID-19 pandemic, the observation was limited to the hospital setting. The type of relationship the adolescents had with their peers and other professionals were included in the observation. The adolescents visited the center once a month, their interactions with other members of the group was observed right after they finished their interviews, noted were taken based on the observation checklist (see Annex III)

Key Informant Interview

With regard to inputs from other sources, a key informant interview guide was developed (See Annex III). Four participants from the ART center participated as key informant interviewees. Another professional from HIV/AIDS Prevention and Control Office (HAPCO) gave an important insight on what the office has been doing to mitigate the different effects of HIV on the study group.

3.10 Data Collection Procedure

How participants were recruited:

The researcher contacted the health care providers at the ART center at Zewditu Memorial Hospital, find those who are responsible to work with the selected group. With the help of the professionals, the researcher selected participants with the above given criteria. Once the researcher found participants and explained to them what the study is about, what their role were and asked if they wanted to participate, they were given a consent form translated in Amharic (See Annex V) to make sure they understand their role in the study. When they said there were not interested or if their guardians did not agree to their participation, they were asked if there is someone they know that fulfills the requirement and would be willing to participate.

All 12 in-depth interviews were conducted face-to-face at the ART center. Two of the key informant interviews took place over the phone while the other two took place face-to-face at the center. The observation was completed at the ART center only. The adolescents were not going to school, and it would be putting into risk both the researcher, the participants and their families if observation at their house was to be carried out.

Period of time required for each type of data collection was expected to take is from 60 to 90 minutes. As the interview is a semi-structured, it would take 60 to 90 minutes to finish. Which is why it was expected to have two sessions, to avoid the boredom and any other issues that come with having to sit for that long. However, after two pilot tests, the researcher deducted the time from 60 to 90 minutes to 45 to 60 minutes, with only one interview session. Once the interviews ended, the adolescents stayed at the center until midday, which gave the researcher enough time to do observation of the type of interaction the participants have with different professionals at the center and other members of the support group.

After the different data collections with the adolescents, the researcher asked health care service providers who had direct relationship with the adolescents. And those who worked at the center for long and who know the behaviors and attitudes of the study group. The interview with these participants took 20 to 30 minutes. Accordingly, four key informant interviews were coducted. Two women and two men. But only two of the practitioners were available for face to face interview at the moment, which led to two of the interviews to be held over the phone.

3.11 Method of Data Analysis

Creswell (2009) also noted that data analysis in qualitative research consists of preparing and organizing the data for analysis, then reducing the data into themes through the process of coding and condensing the codes and finally representing the data in figures, tables or a discussion. Accordingly, interviews were recorded electronically, and field notes were taken during the data collection. The recordings from the interviews were transcribed verbatim and translated to English. Once the data were transcribed it was classified as per the research question of the study. This process was followed by coding to get from unstructured and messy data to ideas about what is going on in the data, it allowed the researcher to simplify and focus on some specific characteristics of the data. During data analysis, the researcher identified four major themes which were also categorized into different sub-themes to help compare results and understand different points.

3.12 Quality Assurance

A scientific research refers to a method free from personal bias or prejudice, a method to ascertain demonstrable qualities of a phenomenon capable of being verified, a method wherein the researcher is guided by the rules of logical reasoning, a method wherein the investigation proceeds in an orderly manner and a method that implies internal consistency (Kothari., 2004). The data gathered are trustworthy as the study used different sources including in-depth interview, observation conducted on the adolescents, and an interview was be conducted with professionals at the health care centre. Literal statements of participants and quotation were used in the analysis as well. However, the time for data collection was lessened because of the state of emergency related to COVID-19 that led to a lockdown for a while. The researcher only got to see the participants of the research once. But the researcher used probing questions, maintained data coherence during analysis, observed the participants during their visit at the ART center. Once the interviews were transcribed, the answers were evaluated and approved by a professional at the center. These methods were used to assure quality and trustworthiness of the data.

3.13 Ethical Consideration

The well-being of the participant must be of top priority over the knowledge to be gained by doing the research (FDRE Ministry of Science and Technology, 2014). According to the national research ethics review guideline, the criteria given as a requirement for a research to be ethical include maintaining privacy and confidentiality, minimization of risk to subjects, and the importance of informed consent where the participants have complete and appropriate knowledge of the study. The participants were first briefed about the purpose and nature of the research and were asked for their informed consent to be involved in the study. The informed consent included the important measures listed out by Neuman (2007):

1. A brief description of the purpose and procedure of the research, including the expected duration of the study.
2. A statement of any risks or discomfort associated with participation.
3. A guarantee of anonymity and the confidentiality of records.
4. The identification of the researcher and of where to receive information about subjects' rights or questions about the study.

5. A statement that participation is completely voluntary and can be terminated at any time without penalty.
6. A statement of alternative procedures that maybe used.
7. A statement of any benefits or compensation provided to subjects and the number of subjects involved.
8. An offer to provide a summary of findings (p. 55).

The informed consent (see Annex IV), was to be signed by caregivers of the adolescents who are under the age of 18. Again, due to the COVID-19 pandemic the researcher settled for an oral consent over the phone. 6 of the adolescents that are 18 signed the informed consent themselves. The informed consent (see annex V) covered the above important measures

Chapter 4: Findings

The result section begins with the demographic profile of the adolescents who participated in the study. Presentation of the finding includes both the domains from literature reviews and the themes drawn using different techniques of data collection. Four main themes arose in the process of analysis. These domains are (1) Aspects of the adolescents' life not affected by HIV (2) Aspects of the adolescents' life negatively affected by HIV (3) Coping strategies and (4) Available support system.

4.1 Sociodemographic Information

Table 4.1 Socio Demographic Information

Participant No.	Age	Sex	Religion	Educational Status	Place of Birth	No. of Siblings	Living Arrangement	Source of Income
1	18	F	Orthodox	2nd year college	A.A.	1	Grandparents	Grandmother
2	18	F	Orthodox	Grade 10	A.A.	1	Both parents	Father
3	18	F	Orthodox	Grade 12	A.A.	0	Both parents	Father
4	18	M	Orthodox	Grade 9	Sululta	6	Aunt	Aunt's husband
5	17	M	Orthodox	Grade 9	A.A.	1	Both parents	Both parents
6	16	M	Orthodox	Grade 9	A.A.	3	Grandmother	Father
7	18	F	Protestant	Grade 9	A.A.	0	Father	Father
8	18	F	Orthodox	Grade 10	A.A.	3	Both parents	Both parents
9	17	M	Orthodox	Grade 10	A.A.	2	Mother	Mother
10	17	F	Orthodox	Grade 10	A.A.	0	Aunts and Uncles	Aunts and Uncles
11	17	M	Orthodox	Grade 11	A.A.	2	Father	Father
12	17	M	Orthodox	Grade 10	A.A.	0	Grandmother	Father

Source: Own survey (May/2020)

4.2 Understanding Different Aspects of HIV

In this study, the topics covered with regard to understanding of different aspects of HIV included, (1) The disclosure process, (2) Experience of stigma and discrimination, (3) The emotional effect it has and (4) The coping mechanisms used by the adolescents to deal with different difficult situations they find themselves in.

Table 4.2 below summarizes the age at which adolescents were informed about their HIV positive status, the person who made the disclosure, the reaction they demonstrated at the time of the disclosure, who provided emotional support once they came to learn they are HIV positive and whether they (the participants) further disclosed their status to anyone else outside of the family.

Table 4.2 – Summary of participants' HIV Status Disclosure, Reaction and Emotional Support

Participant Number	No. of years they have known	Who disclosed status	Reaction	Source of Emotional Support	Have disclosed their status
Participant 1	5	Family	Already knew	Family	Yes
Participant 2	3	Family	Mad	Family	No
Participant 3	5	Family	Cried	Family	No
Participant 4	4	Doctor	Mad	No one	No
Participant 5	4	Family	Shocked	Family	No
Participant 6	6	Family	No Reaction	Family	No
Participant 7	3	Doctor	Already Knew	Family	Yes
Participant 8	4	Doctor	Mad	Family	Yes
Participant 9	9	Doctor	Already Knew	Support Group	No
Participant 10	4	Family	Shocked	Family	No
Participant 11	3	Doctor	Already Knew	No one	No
Participant 12	7	Doctor	Too young to remember	No one	No

4.2.1 Disclosure

In this section a summary of the findings with regard to the age at which their HIV status was revealed to them, how they reacted when they heard their HIV positive status and who was around to support them emotionally at the time of the disclosure and who they have disclosed their status to once they found out are included. Some of the participants reported that their status was revealed when they were as young as nine years old, and others were as old as fifteen years old when they knew their status. As indicated in table 4.2 above, family members and health care professionals were responsible to make the disclosure. As the ART Coordinator explained, even though there isn’t a given age at which the disclosure has to be made, the professionals at the center advice caregivers to tell their children the reality by the age of 10.

With regard to who disclosed the status, family members or close relatives play significant role as equally as doctors. In this regard six of the participant’s had reported they were told about their status either by their parents or a close relative. The remaining six reported they were told by doctors. As reported by the ART coordinator who participated in the study, mostly parents or caregivers do not feel comfortable telling their children that they are HIV positive and request support from doctors to make the disclosing. Adolescents themselves reported that their parents/caregivers who did not see the importance of telling the truth and simply keep sending their children to the ART center to refill their medication. Knowing that some of the adolescents are not aware of their HIV positive status, the health care providers at the ART center decided to reveal the truth for better adherence.

The reactions adolescents claimed they had when they were told their HIV positive status was variant depending on the age and other factors that determine the child’s emotional reaction. For example, two of the participants reported they were too young to understand the consequences of being HIV positive and didn’t have any reactions. On the other hand, other three participants reported they already knew their status based on what they heard about HIV in school or on TV and that they were not surprised when they were told. Four of the 12 participants reported that they got mad or shocked. As an emotional response to the news, three of said the participant’s reported they cried when they were told.

Family members were found to be principal support providers to adolescents once they knew their HIV status as reported by eight of the 12 participants. When it comes to emotional support after finding out their status, eight of the 12 participants had their one or all of their family members' support. But three of them said that they had no one and didn't need emotional support at the moment. One of the participants said that the support group he was in was the one that helped him to go through the hard time.

After finding out their status, nine of the participants said that they did not disclosed their status to anyone, other than a close family member. Their reason was that they wanted to avoid any potential stigma or discrimination that would follow. One of the participants said the following when asked why she has not told anyone about her HIV status:

> I will never tell anyone about this ever. I rather die than share this with anyone. Because you never know, what if the person you thought was your closest friend and you end up fighting and that person shares the secret with everyone. So never. I won't even tell the person I grew up with. She might tell someone she thinks is her close friend, and the other person tells someone they are close to and the next thing I know everyone knows about it and you can never tell how they would react or treat you afterwards. If you tell someone the truth they go and tell someone else how you got the virus doing something you haven't even thought about. (participant No. 2)

A key informant interviewee stated the following about disclosure at the center

"Most caregivers are too scared to tell them, especially if they are not their biological parents. But we tell them to take their time doing it. disclosure is not done once and that's it. We tell them when and where and how it should be done. We make sure they keep us updated. I mean, now if they tell him a week before his exam, the kid is failing, we try to avoid incidents like that" (Key Informant No. 1)

4.2.2 Experienced Stigma and Discrimination

On the aspect of stigma and discrimination, only two of the participants reported that they have experienced stigma and/or discrimination by someone close to them. One of the participants in this study said that she always fought with her grandparents, and that they never treat her right, and back then she did not know what the reason was. She reported:

> I wanted to run away, but to where? My aunts and uncles are exactly like my grandparents. I did not know anyone from my mother's side either, so I was suffering all alone. They made me feel like I was not needed anywhere and back then I didn't even know why. I tried to commit suicide but survived. That is when they brought me to Addis to live with my father. That is when I was told I was HIV positive and that things made sense as to why they were treating me like that. They still don't want me in their lives but at least now I don't care. (Participant No. 7)

The other participant said that his school friends discriminated him back when he was in middle school. He does not know how they found out, but they stopped talking to him, and he decided to isolate himself from his friends and everyone at school. But after a while things started to fade away to the point where everyone forgot about it. And he said that self-isolation has always been his way of avoiding trouble or tough situations.

In addition, key informants said that these adolescents avoid disclosing their status to anyone who is not a family member or a practitioner at the hospital, leading to them not experiencing stigma and discrimination. Nonetheless, one of the counselors at the center said that these adolescents experiencing stigma and discrimination is very common. In the counselor's words:

> Some of the support group members say that they don't even think World AIDS day should be celebrated. They say that they can't even go out and show themselves to the world. So, we (health care service providers) try to convince them that it is not their fault they are HIV positive, and that they should accept the truth. They never even talk about it when they experience stigma and discrimination. They don't even want to share it with their friends in the support group…. (key Informant No. 4)
>
> They are the ones who avoid contacting other because they are afraid of rejection, being stigmatized. But no, I have not had any adolescent complain about being stigmatized or discriminated for their status. In fact some of them complain about the special attention they are getting and wish they were not treated differently that others (Key informant No. 2)

Another key informant interview had a different opinion about stigma and discrimination:

It pains me to see these adolescents keeping themselves away from the society cause they are scared of being judged for who they are. From what you have seen, they are like every other adolescent their age, both physically and mentally. In fact they are more mature, they have the ability and potential to get somewhere in life. But the attitude our society has about these adolescents is negative. Some judge them thinking that they acquired the virus from involving in a sexual relationship. This in turn forced the adolescents to avoid anyone who knows their status in fear of being treated negatively. I really wish the government could do something about it, find ways to teach our society that treating them different is not the right way or that they should not see it with any difference than Diabetics or I don't know….any genetic illness you acquire from your family. (Key Informant 2).

4.3. Aspects of adolescents' life negatively affected by HIV

4.3.1 Emotional Effects

Almost half of the participants said that HIV has an emotional effect on them. They mentioned different reasons as to what cause their emotions to erupt at times. These reasons included the thought of having to take medication on a daily basis for the rest of their lives, the thought of not being able to date or marry whoever they want, when someone who is not a family member (who does not know their status) calls them names or treats them wrong. One of the participants said *"I was shocked and had complex feelings when I found out that I am HIV positive but after I joined the youth group and met others like me, it felt easier." (Participant No. 6)*

The above statement witnesses the emotional effect of HIV/AIDS on adolescents who participated in this study. But when asked if they have been too stressed or worries about any of the reasons, they said that the feelings won't last longer than a few minutes. Furthermore, when asked if they have been depressed, their answer was that there are times where they feel down and sad but they have not had to be declared depressed by any health professional or even felt the depression too long that it has gotten to a level that can lead them to be declared as clinically depressed. A participant said the following about the emotional effects:

It has. A lot. There are days I don't leave my room for three days. I don't eat or leave my bed. There is a feelings I can't explain. One minute I am sad, and not in the mood to do anything, And then it hit me. I go all "what is wrong with you?" and go back to being the happy person I was a few days before. I remind myself that I have a bright future how and that I have to push myself to get there. (Participant 10)

The following are some of the reasons listed by the adolescents as a cause of their emotional disturbance:

- Not being able to do what my friends who don't have the virus in their system can do
- Makes me question everything, why I would be suffering because my father cheated
- I feel lonely, as if I am the only one who is going through this, I feel better when I attend the support group
- When a person calls me names or gets mad at me for something I did, I feel like they are treating me that way because I am HIV positive even though I know that they have no idea what my status is
- Not being able to date whoever I want

Key informant, who is also one of the counselors at the center said the following about the emotional effects:

It should be understood that adolescence is the age where being too emotional is considered normal. They happen to get angry for no reason, or start an argument with a friend or a family member out of the blue, and this is what I expected from an adolescent who is physically and emotionally healthy. Now imagine how these would be exaggerated when it comes to an adolescent with a disease like HIV! I would not blame them for it. I would even tell their caregivers to take it easy on them. It is only worrisome when they don't come out of it for days or weeks. (Key Informant No. 2)

4.4 Aspects of adolescents' life not affected by HIV

4.4.1 Self-esteem as Described by adolescents

According to the adolescent's description of their self-concept and self-esteem, they have revealed that through time at the center and with the help of the support group they have been able to change their understanding of who they think they are and the evaluation of themselves. When asked how they describe their self-concept, 7 of them said that they knew they were like everyone else of their age. They can do or have what they desire. From the questions that followed for more understanding, they made it very clear that they are capable of being their own selves, and that they are exactly like every other adolescent of their age. But two of the participants said that it affects who they are in a way. They think that they are defined by the virus they have in their systems than who they are as an individual. One participant shared his concern as “So in the future, let’s say I am asked to get a medical certificate for a job I want to get hired, but they find out that I am HIV positive and they don’t give me the chance to work for them?” (Participant No. 9)

4.4.2 Meaning to present and future life

When these adolescents were asked how they give meaning to their present life, eight of them said that they are living a life they consider it is good, and that they are happy. Other two participants said that they are living an average life, experiencing ups and downs like every other person. Still other two participants used the word “ለክፉ አይሰጥም”, meaning that they are neither happy nor sad.

Study participants’ response for what they think their future life will looks like, nine of them said that they would be independent, have their own job, move out or get married. Three participants specifically reported that they see themselves in the future they will pay back their parents for taking good care of them at present. One participant reported that her present and future life can be expressed as:

> I am the happiest person ever. Everyone in the family protects me and makes sure I am never be sad or feeling down. And I will have a happy life with my mother in the future. The main difference in the future is that I will be taking care of her instead of her taking care of me. (Participant No. 1)

Ideal life: what they consider an ideal life is the same as what they think their future life will look like. Having a good job, getting married and building a family, having a career path they want, being able to support their family, etc. Specifically, two of the participants said that what they consider an ideal life is if they were able to make enough money to share with the less fortunate.

Educational achievement: Participants' answer to the question "What is the educational level you want to achieve?" some said that they can barely wait until they have their degree, while other six of them reported that they want to go as far as possible. Some claimed that they want a master's degree. And one of the participants said that he wants to have a diploma.

Professional Career: the participants mentioned the following as a career path: healthcare practitioner, manager, fashion designer, photographer, business women/men, civil engineers, actors and astronomers. One participant particularly reported that he wants to be an I.T. specialist. Moreover, he wants to become a part-time social worker:

> Either I.T. or Social work. I want to be a counselor; I am currently talking to an organization to let me be part of their team. I have met some social workers here at the center and what they did was very inspiring so in my spare time I want to involve in social work practice. (Participant No. 9)

Future Life Plans: All of the participants confirmed that they want to get married, have kids and establish a family in the future. Some of them have already some sort of plan which they reported as follows.

> After I graduate and then maybe have my own job will be the time I want to have a boyfriend and think about my future with someone. But I want to be married and live a stress-free life where neither of us care about how long we will live but only care about the happy and big family we will be building. (Participant No. 1)

> I want to graduate first. But I want to have a boyfriend in campus so I will start dating starting my freshman year. Oh I have thought a lot about this. Then we will get married when I graduate. Then we will have a kid after two years of marriage. I don't want to share his love with the new baby. I want him all for myself for at least two years. (Participant No. 2)

> One of the ways we make sure they understand that they can have a future they want is by bringing former members of the group who are currently in a relationship or are married. That helps the adolescents realize that there is a life beyond liking someone. They get to picture themselves in a romantic relationship leading to marriage and building a family. (Key Informant No. 1)

4.4.3 Health and Economic Effects of HIV

Economic effect: All of the participants said that HIV did not affect their economic well-being. None of the participants receive economic support provided by different institutions. Some said that, even if their lives are not fulfilling and cannot call themselves rich, it is not because of the virus. Participant nine has the following assertion when asked if HIV has economic impact on adolescents:

> Economic effect depends on the family's ability to manage money. If you only make a few thousands a month, that means you can only have one child. People know how low their income is and still keep having three, four babies. I say it is not the effect HIV has on them but their ability to manage their income. The HIV counseling and testing is free and so is every other treatment including the pills. Unless they have their own economic problem to begin with, the virus does not affect their economic status. (Participant No. 9)

A key informant had the same opinion about the economic effect of HIV. The ART service is given for free, and transport allowance is covered for those who come to the center. “HIV does not directly affect their economic status but since most of the adolescents come from a very low economic background that can’t even afford to eat three times a day and take their pills.” (Key Informant No. 2)

While the fact is that most of the adolescents struggle economically, those who participated in this study came from a mid-income background. This was caused due to the sampling technique. The researcher used judgmental and snowball sampling, when done with one interviewee, he/she brought someone they thought fulfilled the inclusion criteria but also someone they are friends with or someone they know well. Which led to the result of all participants with a mid-income background.

Health effect: most of the participants reported that they are very healthy. If they are sick, the most serious sickness they had was either common cold, and or a headache. But a few of the participants said that since the virus decrease the body’s ability to fight against different diseases, they have been seriously ill a few times. One of them explained that he had Tuberculosis; the other one said that he had skin rush which he got checked and is better now; and the third one said that she suffers from *peripheral neuropathy* (a nerve damage), which affects her hands since she was born. .

4.5 Challenges and Opportunities of Dating or Establishing Courtship

Most of the participants said they never dated before. But their reasons were not related to the fact that they are HIV positive. Of these participants, a few said that they were too young to start dating or think about courtship and marriage. Others stated that they have no specific reason for not dating. One of the participants said that her religion does not allow her to date at this age, so she has to wait until she is older. Nonetheless, a few of the adolescents said that they were dating and had a boyfriend/girlfriend in the past and that they broke up. All of them dated HIV positive individuals, and the reason they ended the relationship is because they didn’t see a future with that person for different reasons but not because their HIV status interfered in the relationship.

When asked what they think the challenges and opportunities of dating is for adolescents who are HIV positive, they answered the following as what they think are the issues. The answers are not what they think but what their friends and others at the support group think.

Challenges of dating: some said that they think the challenges of dating at this age is the fact that they have to disclose their status to someone who they are not sure will be with them forever, or that at the end of the day they might get hurt. Others said that having to figure out if the person they are dating is HIV negative or positive is hard and it is better to not date than having to break up when the truth is revealed.

Opportunities of dating: When asked what the adolescents thought was the upside of dating while being HIV positive, most of them said that there is someone to understand them and share feelings and worries and that makes life easier. While a couple of them said that they don’t know what the opportunities of dating in their status is.

When to disclose status to boyfriend/girlfriend: The answer participants gave to the question “when would you like to disclose your status to the person you are dating” almost half of them said that they would tell the truth before dating and starting something serious. On the other hand, most of them said that they would reveal the truth through time. One of the participants said that they came up with the following arrangement of how they should reveal their HIV status to the person they are dating:

> There is a system we came up with as a group to tell the person we are dating that we are HIV positive. It is to tell the other person to have the test together and when they tell us we are positive, we pretend like it is the first time we heard a cry and get shocked or anything that will make it look believable. (Participant No. 9)

What we hear about these adolescents' dating like it scary, that they are sexually active and dedicated to transmit the virus to others. But no, these adolescents are decent. Most of them have not even thought about dating. And when the topic is raised during the sessions, they state how they only want to date HIV positive person. They are very mature for their age and want to protect others from going through what they are going through. (Key Informant No. 3)

4.6 Data from Observation

Individuals they interact with

Only a few of the participants seemed shy and not interactive, but the rest were talking and having conversation with most of the support group members. Those who did not interact much had a restricted personality where they seemed to keep themselves from starting a conversation unless someone else talks to them. Two of the participants were also the group leaders, they were going all over the place discussing different topics with different individuals and making sure all the group members had their questions answered or concerns solved.

Activities they involve in:

Since the observation was conducted during a pandemic, the adolescents seemed to have limited themselves with activities that can be done in a few number, which only included playing games with two or three friends or having a conversation with close friends. And none of the participants were seen sitting alone, doing nothing. They all seemed to interact and keep themselves active during their stay.

Type of interaction they have with different professionals:

While all the participants have very good interaction with most of the professionals, they chose all claimed their counselor as their favor. They keep her updated on different events in their lives, or mention to her if they have concerns. They seemed to be happier and more friendly around her. But for the other professionals, the interaction they have is more professional and limited to their time at the center.

4.6 Coping Mechanisms

For the above-mentioned psychosocial problems these adolescents go through, they mentioned different mechanisms as to how they cope with them. Some of them said that one of the ways they use when they feel stressed or sad is listening to music. It gives them momentarily relief from the emotional wreck they go through. A few of them said that reading books helps them forget things. While two of them said that either praying or listening to gospel songs has been effective for them to cope with the emotional effect HIV has on them.

Most of the adolescents seem to have a close to normal ways to cope with the issues they face. They spend their time watching movies, listening to music or gospel songs, reading books, writing poetry and spending time with friends. And their behaviors or attitudes seem positive. They are sociable, friendly and very smiley. And from the researcher's observation, these adolescents were in fact easy to start conversation with, very open about their lives. For some, this was a result of the time they spend at the support group. Some mentioned crying or blaming their parents or the world for what they are going through helped them. A participant mentioned the following of how spending time with her friends helps:

Hanging out with my friends, even if my dad doesn't allow me to go out but I sometimes sneak out to spend time with my friends. I have told you about my best friend, she understands me so much and helps me forget everything. She is not HIV positive but she knows how hard. And sometimes I keep myself busy with books. (Participant 7)

Participant 2 Said the following about the counseling service she gets at the center:

> I told you how everyone in this group is like a family, this place is my home away from home. But counselors ask too one too many questions. Most of the

> questions are about my parents which pisses me off, I sometimes want to remind them that it is about me not my parents. They force me to remember my past, they sometimes make me cry. There were times I left without saying anything because I was tired of it. I don't like being stressed out this much. I mean why do they need to know about my parents this much? My parents don't live my life so I don't want the counselors asking me questions about them.

4.6.1 Spirituality as a coping mechanism

Spirituality in the eyes of the participants is the source and base of life. Eleven of the 12 participants were orthodox and one of them were protestant. Most of them never miss fasting seasons, go to churches on the weekend to attend sermons. Their religion is something they consider very important in their lives. They said that it has an important place in their lives. One participant in particular expressed that spirituality is her source of strength and one of their coping mechanisms but it means more than that. In her own words:

> Especially related to my health. I know I will be healed from this disease. I will be better, not with the help of pills but by myself through prayer and the relationship I build with God. I have been through a lot in my life and my spirituality has been my strength. It has been the reason I am alive. (Participant No 7)

4.7 Available support system

The adolescents mentioned that they get emotional and psychological support from their parents/caregivers, their friends, the support group and their spirituality. One of the participants said the following about his mother:

> Talking to my mother is all the therapy I need. She feels bad for being the reason I am sick and she does everything she possibly can to give me

> everything I need. She is my best friend. The advice she gives me is the reason I am still happy and alive. She is the reason I am mature, happy and have a positive view of the world. Whenever I get home from school and I see her there making snack for me and my siblings makes everything better. (Participant 8)

How has the support group been helpful?

All the participants said that joining the support group, it helped them realize that there are others exactly like them and they no longer felt lonely. Nine of the participants said that they created new friendships and found others whom they can share their worries to with no judgment. Two participants claimed that they are now more confident and have the ability to speak in public. As mentioned above, the support group is held once a week at the ART service. To help include all the service users they are divided into a group of 4, each group comes to the center to the center once in 4 weeks. The group is led by two of the members, one girl and one boy who volunteered to lead and facilitate the program. The group leaders come to the center every week.

Two of the answers that sum up the answers of the other participants is:

> Oh my God, it makes so much difference in our lives. I used to be very shy, I didn’t have confidence and I was never able to even talk with someone for this long. It used to be scary for me but after I joined this group, I am more confident, and I am able to share my thoughts with my friends and anyone around. We are like a family now; we support each other even outside the center. (participant No. 1)

> There are times I leave the house fighting with my father, which happens a lot but I forget everything when I get here. “It is like a break from the world that bothers me”. And when my parents tell me to call them when I get here safe,

I get too excited seeing my friends that I forget to call my parents. (Participant No. 2)

4.8 Summary of Findings

This chapter has highlighted main findings of the study generated using different data collection tools including in-depth interviews, key informant interviews and some observations made in Zewditu Memorial Hospital. The support group has been helping each member to realize that they are not alone. Their self-esteem and self-concept has been shaped by their environment, especially by the support group. In addition, while they are happy with their present life, they see a brighter future where they become more independent and build their own family. Their economic and social status has not been affected by the fact that they are HIV positive. Nevertheless, their emotion is affected easily. Thoughts about dating, not being able to do what their friends who don't have the virus in their system can do, and other issues have caused them emotional stress. Nonetheless, the support they receive from their family and support group, and their spirituality has been a source of strength.

Chapter Five: Discussion

The outbreak of the AIDS epidemic has resulted in different changes that affected the lives of individuals and families. A part of this effect includes the children who have acquired the virus from their mother during perinatal period. HIV-related death among children has decreased due to the introduction of different treatments and drugs, in turn increased the number of children surviving through adolescence and adulthood. As these children enter adolescence, they encounter several psychological issues that present a challenge on their daily lives. This study has highlighted some factors involving the psychosocial impacts of HIV and their description of different aspects of the impacts of the virus.

5.1 Different Aspects of HIV

The study found the disclosure process and factors associated with it, including the age when it was revealed to the children, their reaction, the person responsible for disclosure, the person responsible for emotional support, and who they have disclosed their status to outside the family member. Based on these factors, the study found that some caregivers felt comfortable revealing the status of their children with no worries. But some needed assistance from healthcare providers. Another point the study came to know was the age these adolescents found their status, it varied from 10 to 15 years old. This is consistent with a study conducted by (Biadglign, et al, 2011), the finding of these authors revealed that caregivers preferred disclosure to be delayed until the age of 14. Another study by Roman Negewo (2014), revealed that 68.9% of caregivers preferred the age 10 to 15 to reveal his/her status (p. 30). The reaction of these adolescents was different, those whose status was revealed by their family/caregivers, it made them feel sad, or mad. Some wanted to cry at the moment. Based on a key informant at the center, these reactions are common and expected.

But some have experienced fury. For those whose status was revealed by health care providers, it made them feel mad that their caregivers hid it from them.

After the disclosure process, two main concepts were mentioned. Who these adolescents received emotional support from and who they have disclosed their status to. They have received the emotional support from their caregivers, or someone in the family member. Majority of them leaned on their mother's emotional support. This is in consistent with a study in Zambia, the study showed that the study participants have been receiving emotional support from their family (Zulu & Mumba, 2017). The support group has also been an emotional support on some level. But a few of them did not require the emotional support and went through the moment by themselves. Afterwards, they have not revealed their status to anyone in fear of stigma and discrimination. Those who shared their status with a close friend was so they can have someone to talk about it freely with. On the other hand, most of the adolescents have not shared their status with anyone who is not a family member.

As the findings reveal, there are different types of coping mechanisms these adolescents have. The support they receive has been pushing up their ability to cope with the effects the virus has on them. Their caregivers have been supporting them emotionally in ways that make them realize they have someone they can lean on. The support group for some has been the reason they have better medication adherence which in turn increases their lifespan. These findings have shown that the support group has been a reminder that they are not the only ones who are going through the several impacts HIV has on them confirming what Mupambireyi et al (2014) found in Zimbabwe.

5.2 Self-Esteem as Described by the Adolescents

As the findings of this study, the description of self-concept and self-esteem the adolescents had was pretty much the same with one another. While spending time at the support group, teaching each other what it means to be HIV positive, they have thought themselves they can have what they want in life. They believe that they are like every other adolescent their age.

When seeing the number of those adolescents who happen to be friendly, smiley and easy to talking with, those who enjoy spending time with their friends, watching movies and listening to music, it is clear that they are in fact like every other adolescent of their age. This result is in contrary with a study titled *Evaluation of Psychosocial Adjustment and Self-Esteem in Perinatally HIV-Infected Adolescents;* this study has revealed that adolescents that have been perinatally infected were at high risk of low self-esteem (Louthrenoo, Oberdorfer, Aurpibul & Sirisanthana, 2018). According to the study, low self-esteem is caused due to rejections and physical consequences of HIV. Nevertheless, the participants of this study have not faced rejection or had any physical changes or serious health-related issues, which shows the reason to why they have not claimed to have a low self-esteem.

5.3 Dating and Establishing Courtship

Based on the findings, more number of the participants have the thought of dating and building a future with someone. For most of them, the reason they are not dating right now is because they have other priorities like supporting their parents, being independent and the belief that they are too young to be dating. But they consider having an intimate relationship, get married and have babies in the future. This result is in contrary with a finding of Lowenthal et al. (2014), which found that the desire to have children remains strong in the adolescents, independent of HIV status, but a romantic relationship is typically not regarded as legitimate unless it produces a baby.

Once they start dating, higher number of the participants would want to disclose their status to the person they are dating through time. They want to wait until they are sure the relationship has a serious future, and that he/she won’t leave once they find out the truth. This finding is supported by a study in Zambia; which states that the adolescents do not disclose their status because they fear abandonment or other negative consequences (Mburu et al., 2014).

5.4 Present and Future Life

When it comes to their present and future life, the adolescents seem to have a life they all consider good. They want a future that is different from now in a way that they grow to be independent in different aspects of their lives. They want to be educated, have a job that pays well where they can support their parents, and build a family of their own. The adolescents planned or have thought about a brighter future that they can achieve one goal at a time. This seems to be the result of the sessions they have at the center with individuals who were perinatally infected but are now living a good life. These individuals graduated from different universities, have a job, are independent and are everything the adolescents want to be in the future.

5.5 Health and Economic Effect

Based on a key informant's opinion and observation, most who attend to the ART service come from a low economic background. One of the reasons the service is given for free is so that it can be accessible for those who can barely have a decent meal three times a day. This is contrast to a study in Tanzania, by Ramaiya, et al. (2016); who reported that participants struggled with financial stress. That the negative effects of insufficient household funds and long-term financial uncertainty have led them to different problems. Few of the problems include not having enough transport money to attend medical appointments and collecting their ART. This economic problem does not include the participants of this research. Not only do they receive an allowance once when they come to the center but those who participated in this study come from a mid-income family. This explains why the participants of this study believe that HIV does not have economic effect on their family.

5.6 Emotional Effect

When it comes to the emotional effects of HIV on these adolescents, the study reveals that the reason for their emotional disturbance included not being able to do what others who are at their age who don't have the virus can do. Contracting HIV not because of their own fault, make them to feel like they are the only ones going through this, not being able to date whomever they desire, etc. This result is backed up by a study in South Africa, that stated that perinatally HIV infected children and adolescents are prone or more vulnerable to feeling more emotional due to multitude of sources, including the illness itself, loss of loved ones, as well as fear of rejection and isolation, as a result of stigma and discrimination (Republic of South Africa Department of Health, 2018).

Reasons mentioned above and more lead the adolescents to feel sad, and depressed. But from their responses, the negative feelings they have only last for few hours or maybe a day. Which is not enough to conclude that they are depressed or have other emotional challenges.

5.7 Essence of Spirituality

According to the responses of the study participants spirituality holds a huge place in the lives of perinatally infected adolescents. The participants believe that it is the reason where they are right now. It is what helps them to go through rough times. Based on their answers, they go to church on weekends, never miss fasting seasons, listen to gospel songs and go to church to keep themselves calm when they are going through hard times. This finding has shown that these adolescents use their religion as a coping mechanism and base of their strength, confirming what Ramaiya, et al. (2016), found in their study in Tanzania, the participants made direct reference to a higher power when asked about sources of strength and support and/or how they feel about being HIV positive.

Chapter Six: Conclusion and Recommendation

6.1 Conclusion

Adolescence by itself is a time where different social and psychological problems seem to be magnified, and the problems are worsened by a chronic illness like HIV. The adolescents in the study have had different coping mechanisms on how to deal with their day to day life, one of them being the support group they actively participate in. And from the findings, the researcher concluded that there can be three different important intakes on how their view of the different aspects of HIV are. The conclusion that has been drawn from the findings and the literature reviews has been briefly described in the next section. It also includes social worker's role in addressing different issues and a recommendation.

The adolescents were requested to answer questions related to the different aspects of HIV. Based on the majority number of answers given by the participants, HIV has a negative effect in their emotions. On the contrary, it does not affect their self-concept and self-esteem, thought of present and future life, health and economy. On the topic of support they have been receiving; their caregivers or a member of their family, a close friends and the support group have been providing different types of support. Additionally, their spirituality and their involvement in religion has been a strengthener to help them face the different impacts HIV has.

An arguable topic was their dating life. Despite the fact that their dating life has not been affected by their status, they are aware of the issue on those who are a member of the support group who has a hard time believing that they can date or establish courtship. As the support group coordinator implied they try to solve issues related to dating and establishing courtship by bringing former members of the support group, those who have been married or are currently dating.

The findings of this study have been supported by other findings like Biadglign et al, (2011), Roman Nagewo (2014), Zulu & Mumba (2017) and others. Which provide an insight into the lived experience of HIV positive adolescents that have been infected perinatally. It emphasizes their need for social support and the need to be recognized as a group deserving special attention. The topics that have been in contrary with the findings of other studies including Louthrenoo, Oberdorfer, Aurpibul & Sirisanthana (2018), Ramaiya et al. (2016) and the new topics that have not been studied in depth imply the need for further studies.

6.2 Implication for Social Work Practice

Based on the findings of this study, the following have been proposed as the implication for social work practice. Social work takes place in different contexts and settings. These contexts include individual, education, medical setting and religious institutions. Social workers work to advocate the psychosocial well-being, participation and healthy life of adolescents living with HIV. By creating awareness for the society about the challenges and different effects HIV has on them can lessen the psychosocial effects. For this, there should be well-qualified and competent social workers to provide advocacy and coordinated services. They can be involved in identifying, assessing, describing and evaluating the need for different types of services.

Another important finding of the research was on the importance of the support group for the positive social and emotional status of the adolescents. It implies the need for more number of peer led groups coordinated by more professionals including social workers. If the number of support groups can be increased and led at different hospitals and other settings, the positive effect can be proved. Organizing more number of support group so the positive outcome can also address other adolescents who are struggling with the different effects of HIV is a point not to be missed.

The findings indicated that efforts must be made to strengthen the social network of these adolescents that can provide a supportive system. A network of friends, relatives and involvement in church can be beneficial. In addition, involving caregivers in the counselling service provided at the center can make the service more wholistic in approach.

6.3 Suggestions for Further Research

To further understand the extent to which parts of the adolescents' life HIV affects, there needs to be researches conducted. Future researches should include a quantitative study, to comprise more number of participants. And a qualitative study should be conducted, to be able to include their individual difference. Studies have to be designed to flush out factors that are related to their self-concept and self-esteem, dating and courtship, present and future life, essence of spirituality and the economic, health, emotional and social impacts of HIV on the adolescents' lives. The findings of this study imply that there needs to be more researches conducts on the topics of self-esteem and self-concept, dating and courtship, present and future life, spirituality and economic, health, social and emotional impacts of HIV. This study has a vital input for the issues studied further and fill the gaps were not addressed.

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Annexes

Annex I - In-Depth Interview

Direction: For each of the following questions, you are requested to provide a true statement. It is your right to refuse or discontinue from participating in this study. Finally, I would like to assure you that all your responses would be kept confidential and used only for the purpose of this study.

Part I - Background Information

Age - ____________________ Sex - _____________________ Religion -________________

Education Level - ___________________ Place of Birth - _____________________

1- Who do you currently live with?
2- Do you have siblings?
3- Who is the bread winner in the family?
4- Do you go to school? (If you do, which grade are you in?)
5- Support service provided by different institutions

I- Type of institution - ____

Type of service - ____

II- Type of institution - ____

Type of service - ____

III- Type of institution - ____

Type of service - ____

Part II- Understanding Different aspects of HIV

1- What was the disclosure process like?
  - When did it happen? (How old were you?)
  - Who was responsible for disclosing your status?
  - What was your reaction?

- Who was around to support you emotionally when it happened?
- Who have you disclosed your status to?

2- Have you experienced stigma and discrimination because of your status?

- By whom? How do they know?
- How did it make you feel?
- What was the action you took?

3- What is the emotional effect that HIV has on you?

- Has it caused you to be stressed or to worry too much?
- Have you felt down for a longer period? How long?
- What caused the feeling? What are the reasons that make you fell in particular way?

4- What are/were your coping mechanisms when these things happen?

- Who do you get emotional/psychological support from?
- What are the ways you consider give you emotional strength?
- How often do you attend the support group at Zewditu Memorial Hospital?
- How has the support group been helpful?

Part III – Psychosocial Aspects of HIV/AIDS

1- How do adolescents describe their self-concept and self-esteem?

- What are the things you enjoy doing the most?
- What are the things you consider important in your life? Why are those important?
- What are the behaviors and attitudes that define you?
- How did these behaviors and attitudes become a part of you?
- Do you make important life decisions by yourself?
- If yes, who is the person that helps you make decisions?
- If no, why? (Do you believe you are capable of making decisions by yourself, or is it because there isn't a person to help you with it?)

2- What are the challenges and opportunities of adolescents with HIV in their interest in dating or establishing courtship?

- Do you have a boyfriend/girlfriend?
    - If no, why not?
    - If yes, what is your relationship like? Does he/she know your status?
    - HIV status of the boyfriend/girlfriend?
    - What does your future look like with this person? (*Probe – intimate contact? Marriage? Children?....)
- What does the concept of dating and courtship hold for you in relation to disclosure? (Do you prefer keeping your status a secret? Until when?)

3- How do you express or give meaning to your present and future life?

- What is the ideal life for you? And how is it different or similar to the one you are leading now?
- What is the educational level you hope to achieve? In what field and why?
- What is the career path you hope to follow?
- What have you planned in relation to courtship and building life with a significant other?
- How do you plan to achieve what you consider is an ideal life? (Probe - …marriage, a good job..?)

4- What are the health and economic effects of adolescents' HIV status?

- What are the effects HIV has on your life?
- What are the challenges you faced in relations to your health?
- What are the economic effects it has?
- What are the emotional and mental impacts it has?
- What are the effects it has in their social life?

5- What is the essence of spirituality for adolescents with HIV?

- How do you define spirituality in your own terms?
- What do you say the place spirituality has in your life?
- What do you use your beliefs for?

Thank You!

የተሳታፊዎች ቃለ መጠይቅ

መመሪያ፡ ለሚከተሉት ጥያቄዎች ትክክለኛ እና እውነተኛ መልሶችን ለመስጠት ሞክር/ሞክሪ። ይህንን ጥናት ማቋረጥ ወይም ያለመሳተፍ መብት አለሽ/ህ። የመለሱት ሁሉም መልስ ድብቅ እና ማንም ካንቺ/ካንተ ጋር የሚያያይዘው አደለም። የምጠቀመውም ይህንን ጥናት ሙሉ ለማድረግ ነው።

ክፍል 1 - የግል ማህደር

እድሜ - ____________________ ጾታ - ______________________ ሀይማኖት - __________________

የትምህርት ደረጃ - ____________________ የትውልድ ስፍራ- ______________________

1 አሁን ከማን ጋር ነው የምትኖሪው/የምትኖረው??

2 እህት እና ወንድሞች አሉሽ/አሉህ?

3 ቤት ውስጥ ደሞዝተኛ ወይም የቀን ገቢ ያለው ማነው?

4 ትምህርት ቤት ትሄጃለሽ/ትሄዳለህ? (መልሱ አዎ ከሆነ ስንተኛ ክፍል ነሽ/ነህ?)

ክፍል 2 - የኤች.አይ.ቪን የተለያዩ ገጽታዎች መረዳት

5- ኤች.አይ.ቪ. እንዳለብሽ/ህ ሲነገርህ የነበረው ሂደት እንዴት ነበር?

- መቼ ነበር? (በስንት አመትሽ/ህ?)
- ይህንን ላንተ/ላንቺ መናገር የማን ሃላፊነት ነበር?
- ስሜትሽ/ስሜትህ እንዴት ነበር?
- ስነልቦናዊ ድጋፍ ማን ነበር የሚሰጥሽ/የሚሰጥህ?
- ውጤትህን ከቤተሰብ ውጪ ለማን ተናግረሻል/ተናግረሃል?

6- ማግለል እና መድሎ ደርሶብሽ/ደርሶብህ ያውቃል?

- በማን? እንዴት አወቁ? (ከቤተሰብ አባል ውጪ ከሆነ)
- ምን አይነት ስሜት ተሰማሽ/ተሰማህ?
- የወሰድሽው/የወሰድከው እርምጃ ምንድን ነው?

7- ኤች.አይ.ቪ. ስሜትሽ/ስሜትህ ላይ ያደረሰው ተጽእኖ ምንድን ነው?

- ብዙ እንድታስቢ/እንድታስብ እና እንድትጨነቂ/እንድትጨነቅ አድርጎሻል/አድርጎሃል?
- ለረጅም ጊዜ ወይም ለብዙ ቀናት መጥፎ ስሜት ተሰምቶሽ/ተሰምቶህ ያቃል? ለምን ያህል ጊዜ?

- ይህን ስሜት ምን አመጣው? ይህ ስሜት እንዲሰማሽ/እንዲሰማህ የሚደርግሽ/የሚደርግህ ምንድን ነው?

8- እነዚህ ችግሮች ሲፈጠሩ ለመቋቋም ምን ይረዳሻል/ሃል?

- ስሜታዊ ድጋፍ ከማን ታገኛለሽ/ህ?
- ስነ-አእምሮአው ድጋፍ ከየት ታገኛለሽ/ህ?
- ስሜታዊ ብርታትን ይሰጡኛል የምትያቸው/የምትላቸው ነገሮች ምንድን ናቸው?
- በዘውዲቱ ሆስፒታል የሚሰጠውን የድጋፍ ቡድን በምን ያህል ጊዜ ትከታተያለሽ/ትከታተላለህ?
- ይህ ቡድን ምን ያህል ድጋፍ ሰጥቶሻል/ሃል?

ክፍል 3 -

1 እነዚህ ታዳጊዎች ስለራሳቸው ያላቸውን አስተሳሰብ እና በራስ መተማመን እንዴት ይገልጹታል?

- ለመዝናናት ወይም ጊዜ ለማሳለፍ ምን ታደርጊያለሽ/ህ?
- በህይወትሽ/ህ በጣም አስፈላጊ ናቸው የምትያቸው/የምትላቸው ነገሮች ምንድን ናቸው? ዐስፈላጊ የሆኑት ለምንድን ነው?
- አንቺን/አንተን የሚገልጽሽ/ህ ጸባይና አመለካከት ምንድን ነው?
- እነዚህ ጸባይና አመለካከቶች እንዴት ያንቺ/ያነተ መገለጫ ሆኑ?
- በጣም አስፈላጊ የህይወት ውሳኔዎችን በራስሽ/በራስህ ነው የምትወስኚው/ነው?
- አይ ከሆነ በማን አገዛ ነው የምትወስኚው/ነው?
- አዎ ከሆነ፣ በራስሽ/ህ የመወሰን ችሎታ አለኝ ብለሽ/ህ ታስብያለሽ/ህ?

2 ከኤች.አይ.ቪ ጋር ለሚኖሩ ታዳጊዎች ፍቅረኛ መያዝ ያለው ተግዳሮት እና ጥሩ ጎን ምንድን ነው?

- የወንድ/የሴት ጓደኛ አለሽ/አለህ?
    - አይ ከሆነ ለምን?
    - አዎ ከሆነ ምን አይነት ግንኙነት ነው ያላቸሁ? ያለሽበትን/ያለህበትን የጤና ሁኔታ ያቃል/ታውቃለች?
    - ከዚህ ሰው ጋር ወደፊትሽ/ወደፊትህ ምን ይመስላል?
- ፍቅረኛ መያዝ እና መጠናናት ያለሽበትን/ህበትን ሁኔታ ከመግለጽ ጋር በተገናኝ ምን ታስቢያሽ/ባለህ? -

  እውነታውን ለመናገር ወይስ በሚስጥር ለመያዝ? እስከመቼ?

3 አሁን ያለውን እና የወደፊት ህይወትሽን/ህን እንዴት ትገልጺዋለሽ/ህ?

- ላንቺ/ተ ጥሩ ህይወት ምን አይነት ነው? አሁን ካለሽበት/ህበት ህይወት በምን ይለያያል ወይም ይመሳሰላል?
- በትምህርትሽ/ህ ምን ያህል መጓዝ ትፈልጊያለሽ/ትፈልጋለህ? በምን የትምህርት መስክ?
- በምን አይነት የስራ መስክ ውስጥ መሰማራት ትፈልጊያለሽ/ህ?
- ከተቃራኒ ጾታ ጋር ስላለሽ/ህ ግንኙነት እና የወደፊት ህይወት ምን ታስቢያለሽ/ባለህ?
- ጥሩ ህይወት ነው የምትይውን/ለውን እንዴት ለማሳካት አስበሻል/ሃል?

4 ኤች.አይ.ቪ. በታዳጊዎች ላይ ያለው ኢኮኖሚያዊ እና የጤና ችግር ምንድን ነው?

- በህይወትሽ/ህ ውስጥ ያመጣው ችግር ምንድን ነው?
- በጤናሽ/ህ ላይ ያለው ችግር ምንድን ነው?
- በኢኮኖሚ ላይ ያለው ችግር ምንድን ነው?
- በስነ-ልቦናሽ/ህ ላይ ያለው ችግር ምንድን ነው?
- በማህበራዊ ኑሮሽ/ህ ላይ ያለው ችግር ምንድን ነው?

5 እምነት በነዚህ ታዳጊዎች ላይ ያለው ትርም ምንድን ነው?

- እምነትን እንዴት ትገልጺዋለሽ/ጻዋለህ?
- እምነትን ባንቺ ቃል ግለጺልኝ/ጽልኝ.
- እምነት በህይወትሽ/ህ ውስጥ ምን ቦታ አለው?
- እምነትሽን/ህን ለምን ጥቅም ታውይዋለሽ/ህ?

አመሰግናለሁ!

Annex II - Observation Checklist

Observation at the Hospital Setting

- Individuals they interact with
- Activities they involve in
- Type of interaction they have with different professionals

Annex III - Practitioner interview guideline

This study will be conducted by Edlawit Wondimu, Second Degree student at Addis Ababa University, School of Social Work. I am collecting data for my thesis project titled *exploring the Psychosocial Aspects of Perinatally infected adolescents: the case of adolescents using the outpatient Anti-Retroviral Therapy service at Zewditu Memorial Hospital, who attend the weekly peer support group sessions.* I would use the information we generate to the best use of my research while simultaneously provide a clear picture of the psychosocial aspects of HIV/AIDS on the adolescents who have been infected perinatally.

Background Questions

Sex - ______________

Educational Level - _________________________

Profession - _________________

Years of Experience - _____

Role in the Center - ________________________

1- How long have you worked at the ART center?

2- Have you had experience of having to disclose the HIV status of service users?
   - What were the reactions?
   - What kind of service does the center offer for the different reactions of the service users?

3- What are you views and experiences of stigma and discrimination towards these adolescents?

4- Does HIV have a negative impact on their mental health?
   - What are the most common mental health issues faced by these adolescents?
   - How has it been addressed by different professionals in the center?

5- What are some of the most common coping mechanisms used by the adolescents?

  - How effective have they been?

6- What are the negative impacts the virus has on them?

  - Does it have economic impact? How?
  - Does it have social impact? How?
  - Does it have emotional impact? How?
  - Does it have psychological impact? How?

7- How has the virus affected their self-esteem?

8- Do they easily interact with one another? And with the opposite gender?

9- How has the virus affected the view they have of the future?

10- Any last comments or remarks?

Thank You!

የባለሙያዎች ቃለ መጠይቅ

ይህን ጥናት የማጠናው እድላዊት ወንድሙ እባላለሁ። በአዲስ አበባ ዩንቨርስቲ ሁለተኛ አመት የሶሻል ወርክ ተማሪ ነኝ። በአሁኑ ሰአት መመረቂያ ጽሁፌን ከእናት ወደ ልጅ ኤች.አይ.ቪ. የተላለፈባቸው ታዳጊዎች እና በዘውዲቱ ሆስፒታል ሳምንታዊውን የአቻ ለአቻ ቡድን የሚከታተሉ ታዳጊዎች ላይ ነው የምሰራው። የምሰበስበው መረጃ የጥናት ጽሁፌን ከማጠናከሩም በላይ ለሌሎች ሰዎች ኤች.አይ.ቪ. በነዚህ ታዳጊዎች ላይ ያለውን ስነ-ልቦናዊ እና ማህበራዊ ገጽታውን ያሳያል።

<u>የግል መረጃ</u>

ጾታ - ________________

የትምህርት ደረጃ - ______________________________

ሙያ - ____________________

የስራ ልምድ - ______

በማእከሉ ያለዎት ሚና - _____________________________

1- በማእከሉምን ያህል ሰርተዋል?

2- ጥናት ለሚደረግባቸው ታዳጊዎች የኤች.አይ.ቪ. ውጤታቸውን ተናግረው ያውቃሉ?

  - ምን አይነት ምላሽ ነበራቸው?
  - መእከሉ ውጤታቸው ሲነገራቸው ተከትሎ ለሚመጣው ምላሽ ምን አይነት አገልግሎት ይሰጣል?

3- በነዚህ ታዳጊዎች ላይ ስለሚደርሰው ማግለል እና መድሎ ምን አይነት አስተያየት አለዎት?

4- ኤች.አይ.ቪ. በአእምሮ ጤናቸው ላይ ምን አይነት አሉታዊ ተጽእኖ አለው?

  - እነዚህ ታዳጊዎች በተደጋጋሚ የሚያጋጥሟቸው የአእምሮ ጤና እክሎች ምንድን ናቸው??
  - አነዚህ ችግሮች በማእከሉ እንዴት ተደራሽ ተደርገዋል?

5- የሚያጋጥሟቸውን ችግሮች ለመቋቋም ምን መንገዶችን ይጠቀማሉ?

  - አነዚህ መንገዶች ምን ያህል ውጤታማ ናቸው?

6- ቫይረሱ ህይወታቸው ላይ ያለው አሉታዊ ተጽእኖ ምንድን ነው?

  - ኢኮኖሚያዊ ተጽእኖው ምንድን ነው?
  - ማህበራዊ ተጽእኖው ምንድን ነው?

- ስሜታቸው ላይ ያለው ተጽእኖ ምንድን ነው?
- ስነ-ልበናቸው ላይ ያለው ተጽእኖ ምንድን ነው?

7- ቫይረሱ በራስ መተማመናቸውን ጎድቶታል? እንዴት?

8- ከሌሎች ጋር በቀላሉ ይግባባሉ? ከተቃራኒ ጾታ ጋርስ?

9- ከቫይረሱ ጋር መኖራቸው ስለወደፊት ያላቸው አስተሳሰብ ላይ ተጽእኖ አለው? እንዴት?

10-በመጨረሻ አስተያየት ወይም ተጨማሪ መረጃ ካለዎት፡፡

አመሰግናለሁ!

Annex IV - Caregiver's consent for Child

My name is Edlawit Wondimu. I am from Addis Ababa University, second year Social Work Maters student. I am collecting data for my thesis project titled *Exploring the Psychosocial Aspects of Perinatally infected adolescents: the case of adolescents using the outpatient Anti-Retroviral Therapy service at Zewditu Memorial Hospital, who attend the weekly peer support group sessions.* I would use the information we generate to the best use of my research while simultaneously providing a clear picture of the psychosocial aspects of HIV/AIDS on the adolescents who have been infected perinatally. By participating in the study, I am obliged to make sure your child's well-being is my priority and that he/she will be in no harm. The following is all the information you need to understand before signing.

I understand that the participation of my child is voluntary. My child has a right to withdraw his/her consent to participate at any time without penalty and also have a right not to answer any question that makes him/her feel uncomfortable. I understand that confidentiality will always be maintained. The person asking my child questions will never tell anyone what my child has said. No one will be able to link my child‘s name to the answers given. My child‘s privacy will be maintained in all published and written data resulting from this study.

I understand that there might be no financial benefit to my child as an individual and that one possible limitation of participating in the interview is that my child may experience intense emotions due to recalling difficult experiences in his/her life. In the event that this should happen, you will refer my child to an organization that can give him/her assistance and support. In my opinion, my child understands the nature of the study and is willing to participate. I understand that the interview will not be a one-time thing, that it has phases with different personal and private questions.

The finding of this study will be presented and reported to the Addis Ababa University, School of Social Work. I will be offered a copy of the summary of the findings. I agree that my child participates in this study.

Signature of parent/caregiver _____________ I consent to my child's participation

Date: ____________

You can take this copy of the consent document to keep

Here is the address of the counselor your child can go to in case of emotional disturbance due to recalling difficult experiences:

Sister Tizita Weldeyesus – Counselor at the ART clinic

If you need more clarification, have concerns or questions feel free to contact the researcher on

Phone No. - +251 913 833 830

Email – Edil.Amanuel@yahoo.com

Name – Edlawit Wondimu

Or **Addis Ababa University, School of Social Work**

Phone No. – +251 11 122 5950

የወላጅ ወይም ያሳዳጊ ፍቃድ መጠየቂያ ፎርም

ይህን ጥናት የማጠናው እድላዊት ወንድሙ እባላለሁ። በአዲስ አበባ ዩንቨርስቲ ሁለተኛ አመት የሶሻል ወርክ ተማሪ ነኝ። በአሁኑ ሰአት መመረቂያ ጽሁፌን ከእናት ወደ ልጅ ኤች.አይ.ቪ. የተላለፈባቸው ታዳጊዎች እና በዘውዲቱ ሆስፒታል ሳምንታዊውን የአቻ ለአቻ ቡድን የሚከታተሉ ታዳጊዎች ላይ ነው የምሰራው። የምሰበስበው መረጃ የጥናት ጽሁፌን ከማጠናከሩም በላይ ለሌሎች ሰዎች ኤች.አይ.ቪ. በነዚህ ታዳጊዎች ላይ ያለውን ስነ-ልቦናዊ እና ማህበራዊ ገጽታውን ያሳያል።

ልጅዎ በዚህ ጥናት በመሳትፏ/ፉ የመጀመሪያ ግዴታዬ ደህንነቷን/ቱን መጠበቅ እና ምንም አይነት ጉዳት እንደማይደርስበት ማረጋገጥ ነው። የሚከተለውን ከመፈረምዎ በፊት ማወቅ ያለብዎት መረጃ ነው።

የልጄ ተሳትፎ በፍላጎት መሆኑን አውቃለሁ። ልጄ በማንኛውም ሰአት ተሳትፎዋን/ውን ማቋረጥ እንደምትችል/ሚችል እና ለአንዳንድ ጥያቄዎች መልስ አለመስጠት መብት እንዳላት/እንዳለው አውቃለሁ። የሚጠይቀው ሰው የልጄን መልስ ለማንም እንደማይናገር አውቃለሁ። የልጄን መልስ ከስሟ/ከስሙ ጋር ማንም ሊያገናኘው አይችልም።

ልጄ በዚህ ጥናት መሳተፍ እንደግለሰብ ምንም አይነት የገንዘብም ሆን ሌላ ጥቅማ ጥቅም እንደሌለው አውቃለሁ። በዚህ ጥናት ልጄ በመሳተፏ/ፉ እና ያለፉ ነገሮችን በማስታወስ ለሚመጣው የስሜት ለውጥ የጥናቱ ባለቤት ድጋፍ ሊያደርግላት/ለት የሚችል ግለሰብ ጋር እንደሚመራት አውቃለሁ። ልጄ ይህንን ሁሉ እነደምትረዳ/እንደሚረዳ እና ለመሳተፍ ሙሉ ለሙሉ ፈቃደኛ እንደሆነች/እንደሆነ አውቃለሁ።

የዚህ ጥናት ውጤት ለአዲስ አበባ ዩንቨርስቲ ሶሻል ወርክ ትምህርት ክፍል እንደሚቀርብ እና የመጨረሻውን ውጤት ቅጂም መውሰድ እንደምችል አውቃለሁ። ልጄ በዚህ ጥናት ውስጥ እንዲሳተፍ እስማማለሁ።

የወላጅ/አሳዳጊ ፊርማ ___________ በልጄ ተሳትፎ ተስማምቼ እፈርማለሁ። ቀን: _____________

ልጅዎት ምንም አይነት የስነልቦና ድጋፍ ቢያስፈልጋት/ገው በዚህ አድራሻ ማግኘት ይችላል።

ሲስተር ትዝታ ወልደየሱስ ስልክ ቁጥር - 09 11 81 21 83

ሌላ መረጃ ካስፈለገዎት፣ ጥያቄ ወይም ሃሳብ ካለዎት በሚከተሉት አድራሻዎች መጠቀም ይችላሉ።

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ወይም አዲስ አበባ ዩኒቨርስቲ፣ ሶሻል ወርክ ትምህርት ክፍል

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Annex V - Informed Consent

My name is Edlawit Wondimu. I am from Addis Ababa University, second year Social Work Maters student. I am collecting data for my thesis project titled *Exploring the Psychosocial Aspects of Perinatally HIV infected adolescents: the case of adolescents using the outpatient Anti-Retroviral Therapy service at Zewditu Memorial Hospital, who attend the weekly peer support group sessions.* I would use the information we generate to the best use of my research while simultaneously provide a clear picture of the psychosocial aspects of HIV/AIDS on the adolescents who have been infected perinatally.

Your participation is voluntary and that you have the right to withdraw your consent anytime with no penalty. Confidentiality will always be maintained, I will not be telling the information I received from you for my friends, colleagues or anyone around me. No one will be able to link your name to the answers given. I have a few personal questions to ask, which means privacy will be maintained in all the written data. You need to understand that the interview is expected to last from and hour to 90 minutes. There are two different parts with different type of questions we need to cover. Hence, we will have two different sessions to cover all the parts.

Understand that there might be no financial benefit as an individual and that one possible limitation of participating in the interview is that you may experience intense emotions due to recalling difficult experiences in your life. If this should happen, you will be referred to an organization that can give you assistance and support.

The finding of this study will be presented and reported to the Addis Ababa University, Graduate school of Social Work. When the findings are reported you will not be identified. You will be offered a copy of the summary of the findings. And I would very much appreciate your participation in the study, sign here if you are willing.

Signature if interviewee ___________ Signature of the interviewer _______________

Date _______________

You can take this copy of the consent document to keep

Here is the address of the counselor your child can go to in case of emotional disturbance due to recalling difficult experiences:

Sister Tizita Weldeyesus – Counselor at the ART clinic.

If you need more clarification, have concerns or questions feel free to contact the researcher on

Phone No. - +251 913 833 830

Email – Edil.Amanuel@yahoo.com

Name – Edlawit Wondimu

Or **Addis Ababa University, School of Social Work**

Phone No. – +251 11 122 5950

የተሳትፎ ፈቃድ መጠየቂያ ፎርም

ይህን ጥናት የማጠናው እድላዊት ወንድሙ እባላለሁ። በአዲስ አበባ ዩንቨርስቲ ሁለተኛ አመት የሶሻል ወርክ ተማሪ ነኝ። በአሁኑ ሰአት መመረቂያ ጽሁፌን ከእናት ወደ ልጅ ኤች.አይ.ቪ. የተላለፈባቸው ታዳጊዎች እና በዘውዲቱ ሆስፒታል ሳምንታዊውን የአቻ ለአቻ ቡድን የሚከታተሉ ታዳጊዎች ላይ ነው የምሰራው። የምሰበስበው መረጃ የጥናት ጽሁፌን ከማጠናከሩም በላይ ለሌሎች ሰዎች ኤች.አይ.ቪ. በነዚህ ታዳጊዎች ላይ ያለውን ስነ-ልቦናዊ እና ማህበራዊ ገጽታውን ያሳያል።

በዚህ ጥናት የመሳተፍ ሙሉ መብት አለሽ/ህ፤ በተጨማሪም ያለምንም ቅጣት ማቋረጥ ትችያለሽ/ህ። አንዳንድ የግል ሚስጥሮችን ልጠይቅ እችላለሁ። ሚስጥራዊነቱ ሙሉ በሙሉ የተጠበቀ ነው። ይህንን መረጃ ለጓደኞቼም ሆነ ለሌሎች አልናገርም። ስምሽን/ህን ከሰጠሽው/ኸው መልስ ጋር ማንም ሊያገናኘው አይችልም። ቃለመጠይቁ ከ45-60 ደቂቃ የሚፈጅ እና ሁለት ክፍሎች ያሉት ነው። በዚህ ጥናት ውስጥ መሳተፍ ምንም አይነት የገንዘብም ሆነ የቁስ ድጋፍ የለውም። በተጨማሪም አንዳንድ የድሮ ታሪኮችን ለማስታወስ ለሚፈጠሩ ስሜቶች ድጋፍ የሚያደርግ ግለሰብ ጋር ትመሪያለሽ/ህ።

የዚህ ጥናት ውጤት ለአዲስ አበባ ዩንቨርስቲ ሶሻል ወርክ ትምህርት ክፍል የሚቀርብ ይሆናል። ውጤቱ ሲቀርብ ላንቺም/ላንተም ቅጂ ይሰጥሻል/ይሰጥሀል። ለመሳተፍ ከወሰንሽ/ከወሰንክ ከስር ባለው ቦታ ላይ ፈርሚ/ም። ለተሳትፎሽ/ህ በጣም አመሰግናለሁ።

ቃለመጠይቅ የተደረገው ሰው ፊርማ ______________ ቃለመጠይቅ አድራጊው ፊርማ ___________________

ቀን ___________________

*ይህንን ቅጂ መውሰድ ይችላሉ።

ስነልቦና ድጋፍ ቢያስፈልግሽ/ህ በዚህ አድራሻ ማግኘት ይችላል።

ሲስተር ትዝታ ወልደየሱስ - ስልክ ቁጥር - 09 11 81 21 83

ሌላ መረጃ ካስፈለገዎት፣ ጥያቄ ወይም ሃሳብ ካለዎት በሚከተሉት አድራሻዎች መጠቀም ይችላሉ።

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