ADDIS ABABA UNIVERSITY

COLLEGE OF SOCIAL SCIENCE

SCHOOL OF SOCIAL WOK

Children Living With HIV/AIDS in Kolfe Keraniyo Sub-City: What Contributes to an HIV Positive Child Psychosocial Thriving? A Qualitative Study

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Children Living With HIV/AIDS in Kolfe Keraniyo Sub-City: What Contributes to an HIV Positive Child Psychosocial Thriving? A Qualitative Study

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School of Social Work

This is to certify that the thesis prepared by Gashaw Aragie, titled: '*Children Living with HIV/AIDS in Kolfe Keraniyo sub-city: What Contributes to an HIV Positive Child Psychosocial Thriving?'* and submitted in partial fulfillment of the requirements for the Degree of Master of Social Work compiles with the regulations of the University and meets the accepted standards with respect to originality and quality.

Signed by the Examining Committee:

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Examiner _________________ Signature ___________ Date ______________

Advisor __________________ Signature ___________ Date ______________

DECLARATION

I declare that *CHILDREN LIVING WITH HIV/AIDS IN KOLFE KERANIYO SUB-CITY: WHAT CONTRIBUTES TO AN HIV POSITIV CHILD PSYCHOSOCIAL THRIVING* is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

. . . .   **February 2015**

Signature   **Date**

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Table of Contents

Acronyms ix

Chapter One: Introduction 1

1.1. Background of the research 1

1.2. Situating the problem 3

1.3. Statement of the Problem 4

1.4. Operational Definition of Terms 7

1.5. Objectives 8

1.6. Significance of the study 8

1.7. Limitation of the Study 9

1.8. Organization of the paper 10

Chapter Two: Literature Review and Theoretical Framework 11

2.1. Literature Review 11

2.1.1. Literature on disclosure of children's HIV statues 11

2.1.2. Literature on stigma 16

2.1.3. Psychosocial support 20

2.1.4. Literatures about children living with HIV/AIDS in Ethiopia 26

2.2. Conceptual Definitions 31

2.2.1. Child 31

2.2.2. HIV infected Child 32

2.2.3. HIV/AIDS 32

2.2.4. Thriving 34

2.1.5. Psychosocial Support 34

2.3. Theoretical Framework 36

2.3.1. Bronfenbrenner's Ecological Systems Theory 37

3.1. Research Design 43

3.2. Study Area and participants 43

3.3. Sampling Techniques 45

3.4. Data collection Procedures 45

3.5. Data Analysis 49

3.6. Ethical Considerations 50

Chapter Four: Results 52

4.1. Socio-demographic characteristics of respondents 52

4.1. Positive thriving resources 53

4.1.1. Knowing own HIV status 53

4.1.2. Supportive relationships 55

4.1.3. Leisure Activities for psychosocial wellbeing 58

4.2. Differences in psychosocial living with HIV before and after disclosure 60

4.2.1. Knowledge about HIV 60

4.2.2. Understanding Life situations 61

4.3. How to deal with Stigma 63

4.3.1. Protect themselves 63

4.3.2. Confidence Development 64

Chapter Five: Discussions and Recommendation 66

5.1. Discussions 66

5.1.1. HIV status disclosure as a positive resource 66

5.1.2. Disclosure enabling children to take care of themselves ... 70
5.1.3. Disclosure to understanding life situation ... 71
5.1.4. Disclosure in relation to access social support ... 72
5.1.5. Disclosure in relation to handling HIV associated stigma ... 75
5.1.6. Disclosure in relation to psychosocial well-being ... 77
5.2. The treatment system as a positive resource ... 78
5.2.1. Medical advice and counseling ... 78
5.2.2. Antiretroviral treatment ... 79
5.3. The Socio-ecological Theory and HIV affected children ... 80
5.4. Recommendations ... 81
References ... 83
Appendices ... 90

List of figures and tables

Figure1. Socio Ecological Theory Model ... 40
Table 1: Overview of Participants ... 52

Acronyms

ACRWC African Charter on the Right and Welfare of a Child

AIDS Acquired Immunodeficiency Syndrome

ART Anti-retroviral Treatment

CBO Community Based Organization

CRS Catholic Relief Service

CSA Central Statistics Authority

FDRE Federal Democratic Republic of Ethiopia

FSCE Forum for Sustainable Child Empowerment

FHAPCO Federal HIV/AIDS Prevention and Control Office

HACI Hope for African Children Initiative

HIV Human Immunodeficiency Virus

HVC Highly vulnerable children

HSRC Human Sciences and Research Council

MOJ Ministry of Justice

MOH Ministry of Health

MOWCYA Ministry of Women, Children, and Youth Affairs

NGO Non-Governmental Organization

PSS Psychosocial Support

REPSSI Regional Psychosocial Support Initiative

SADC South African Development Community

SSA Sub-Saharan Africa

UNAIDS The joint United Nations Programs on HIV/AIDS

UNCRC United Nations Convention on the Rights of a Child

UNICEF United Nations Children's Fund

WHO World Health Organization

YPLHIV Young People Living with HIV/AIDS

ABSTRACT

Ethiopia has among the highest HIV infection rate in the Sub-Saharan Africa and the epidemic has left a large proportion of children and adolescents living with HIV/AIDS. HIV positive children's psychosocial well-being is at risk due to the confounding variables associated with the epidemic though the antiretroviral medications are contributing to more HIV positive children surviving into adolescence and adulthood.

This qualitative research has employed a phenomenological approach in an attempt to understand what makes those children living with HIV psychosocially thrive and what available support mechanisms make the children successful for their future live from the perspective of the children. The study involved focus group discussion, interview and observation in *Kolfe Keraniyo* sub-city of Addis Ababa for evidence gathering from 26 selected children living with HIV (aged 10 to18) and key informants from the ART center and an organization working with those children in the sub-city.

It was found out that non-off the participants were disclosed their HIV status to peers, neighbors, and school communities, but to parent(s), very close relative and health workers at ART center. Selective friendship, avoidance of people that talk against individuals who live with HIV and AIDS, selective HIV status disclosure to family member, and spending most of their time on leisure activities were the positive resources that children involved in this study used. The need to provide special recognition and support to children living with HIV/AIDS by service providers and policy makers in Addis Ababa is underlined.

Chapter One: Introduction

1.1. Background of the research

Identification of a research problem involves choosing a research topic, but the inspirational factors that fascinated researchers - for example, by their own life experiences and observations- in the first place could be one good reason for identifying a research problem (Kothari, 2004). The motivation behind this particular research was articulated in understanding to the growing number children living with the HIV and AIDS and explores the psychosocial experiences of children living with HIV who have been receiving the care and support services under the category of highly vulnerable children (HVC) from an organization.

Whatever low or high the figure might be, no one can underestimate the severe impact of AIDS-related psychosocial problems on the lives of children living in poor families due to HIV associated stigma and its threat to Ethiopia's long-term human developmental endeavors.

Children living with HIV are a special group, even within the category of highly vulnerable children, with their own unique challenges and needs -frequent illness, hospitalization, poor environmental conditions, social instability, parental illness and peer pressure (Amzel et al., 2013; Richter, Foster, and Sherr, 2006; Sherr, 2005). Due to their limited physical and emotional development, lack of basic needs and support, and HIV-related neglect, stigma and discrimination, these children could find it hard to earn a satisfactory childhood living instead their physical and psychosocial development are negatively affected directly and often simultaneously (CRS, 2009; Mavhu et al., 2013).

Yet they are overshadowed by other vulnerable groups like who lost their parent(s) due to AIDS and poverty, and receive great attentions from different program implementing organizations (Deacon and Stephney, 2007).

Besides to this in Ethiopia policy makers, advocacy groups, service providers and the community gave little or no attention to these children due to different factors, including the lack of research on the subject. However, many research and intervention programs in the SSA, including Ethiopia gave it little attention and continued to focus on the more visible impacts of these crises. For example, feeding programs for orphaned children, ART programs for HIV-infected people, cash transfers and so on are given more emphasis (FSCE, 2006; Mavhu et al, 2013; and REPSSI, 2008). Previous psychosocial studies have also given more attention to disclosure of children's and adolescents' HIV status in relation to barriers to disclosure (Abebe and Teferra, 2012; Sibhatu et al., 2011; Vaz LME et al., 2011), positive effects of disclosure (Digsu et al., 2012; and Vaz L, et al., 2010) and the disclosure process in itself (Sherr, 2005).

Children infected with HIV/AIDS with their unique needs and challenges have been such an exceptional phenomenon that triggered the following research question: *What makes an HIV positive child age between 10 to 18 years old in Kolfe Keraniyo sub-city of Addis Ababa thrive his/her psychosocial situations and preparing for his/her future?* Therefore, it was found worth in exploring the psychosocial thriving mechanisms that those HIV positive children adopt in their environment including home, neighbors, healthcare centers and schools in Kolfe Keraniyo sub-city.

1.2. Situating the problem

The HIV/AIDS is increasingly affecting the health and welfare of children and undermining hard-won gains of child survival particularly in highly affected countries (WHO and UNICEF, 2008). Recent estimates from the Joint United Nations AIDS Programs (UNAIDS) suggest that globally about 3.4 million children younger than 15 years of age are living with HIV in 2012 alone and an estimated 250,000 children under age of 15 years were died due to AIDS related cases globally in 2011(UNAIDS, 2012). Sub-Saharan Africa, a region with only 12 percent of the global population, remains the most heavily affected region by HIV (Amzel et al., 2013; CRDA, 2006; UNAIDS, 2012; UNAIDS, WHO and UNICEF, 2010). In 2011 alone about 70 percent of all children living with HIV and more than 50 percent of deaths from AIDS-related illnesses in children`s occurred in this region (USAIDS, 2012).

Ethiopia is one of the countries worst affected by HIV and AIDS in many respects in the region. Even if there are reports about the reduction of national HIV prevalence rates from an estimated 2.4% in 2010 to 1.5% in 2011, Ethiopia carries one of the largest HIV disease burdens in the SSA region (FHAPCO and MOH, 2011). Literatures estimated that 793,700 people living with HIV of which children accounts to 200,300 were living in Ethiopia in 2013 alone (FHAPCO, 2014). According to the federal HAPCO at the end of 2013 out of estimated 200,300 children living with HIV, 18, 931(9.5%) were started on ART, while 17,677 were on ART in 2012 (CSA and ICF, 2011; FHAPCO, 2014; FHAPCO and MOH, 2011). The 2011 DHS explained that the urban administrations of Addis Ababa was one of the regions with the highest prevalence of HIV and AIDS for example, the information indicated that out of the total 86,223

people living with HIV in Addis Ababa, 7,035 are children who are living with the epidemic (FHAPCO, 2014; FHAPCO and MOH, 2011).

These statistics demonstrate that significant numbers of children and adolescents in the world and particularly in Africa and Ethiopia as well are still becoming infected with HIV on a consistent basis. Once these children receive their HIV diagnosis, they must contend with adjusting to the news that they are now living with a chronic health condition that requires long-term medical management (Deacon and Stephney, 2006; UNAIDS, 2004).

The HIV epidemic has an enormous impact on affected children of the SSA, nearly every aspect of their lives: economical, educational, physical, social and psychological aspects of their life (CRS, 2006; FHAPCO and MOH, 2011; Richter et al., 2006; Sherr, 2005). The effects of the HIV epidemic on children in SSA is also compounded by the fact that many families live in communities who are already disadvantaged by poverty, poor infrastructure and limited access to basic services (UNAIDS, 2004:41).

In view of these realities, this research sought to explore those resources that contribute for HIV positive children ages between 10 to 18 years thriving the psychosocial experiences and prepare for their future.

1.3. Statement of the Problem

Studies indicate that in the Sub-Saharan Africa (SSA) without treatment 75% of HIV-infected children were die before their fifth birthday (WHO, 2009 and 2011). In Ethiopia there were about 200,300 children less than 15 years of age living with HIV/AIDS in 2014 alone. Reports support the small coverage of children living with

HIV getting ART, for example, about 16,000 in 2011, 17, 677 in 2012 and 18,931 in 2013 children living with HIV got antiretroviral treatment(ART) (FHAPCO, 2012; FHAPCO, 2014).

Accessibility of free highly active antiretroviral treatment (HAART) to these children has markedly reduced AIDS-related mortality rates, and HIV-infected children are living longer healthier lives into adolescence and adulthood (Amzel e al., 2013; CRS, 2009; FHAPCO, 2010; UNAIDS, 2012; WHO, 2011). Literatures show that this significant increment in the survival rates of infants and young children creates new risky environments that expose them and their caregivers for several challenges (Amzel et al., 2013; Kanesathasan et al., 2011; Richard et al., 2006; Sherr, 2005). Their childhoods, therefore, have been characterized by frequent illness, hospitalization, poor nutrition and school attendance (Kanesathasan et al, 2011; Mavhu et al., 2013), intellectual impairment and skin disfiguration (Sherr, 2005), discrimination, social rejection and isolation (Bikaako-Kajura et al., 2006; Hejoaka, 2009).

Moreover, HIV infection often requires that these children threaten with multiple challenges as they age, such as bereavement of lost caregivers and family members, issues involving disclosure, and difficulties in understanding of ART and adherence (Amzel et al, 2013; Mavhu et al., 2013; Richter et al., 2006). The majority of vulnerable children including those who live with the HIV- epidemic in Africa who lost their parents are mainly cared for by extended families. However, because of poverty and the stresses and destitution associated with the AIDS epidemic are negatively affecting family networks and communities where children's wellbeing and their emotional, social, health

and educational outcomes are dependent on supportive families and communities (CRS, 2009; Mavhu et al., 2013).

Any one or combination of these variables puts a child at risk for psychosocial difficulties, which is defined as the inability to successfully cope with aspects of one's life, resulting in changes in personality, due to prolonged emotional stress, and a lack of social functioning (Sherr, 2005). However, many research and intervention programs in the SSA have given little attention to the psychosocial impacts of HIV on children living with the epidemic (Richter et al., 2006). Instead, they continued to focus mainly on the more visible impacts of these crises; for example, feeding programs for orphaned children (CRDA, 2006), ART programs for HIV-infected people, cash transfers and so on (FSCE, 2006; Mavhu et al, 2013; REPSSI, 2008). Richter et al. (2006) supported the limitations and indicated the economic impact of HIV/AIDS on children living with HIV in SSA has overshadowed the concern about the psychosocial impact of HIV/AIDS epidemic on these children (Deacon and Stephney, 2007). What make these children thrive the psychosocial events in their day-to-day lives in Addis Ababa has not gotten more attention in Ethiopia. Knowledge about what promotes positive health and psychosocial well-being in this group is very important in order to enable them to improve and sustain their quality of life.

In view of these realities, this research sought to explore the positive factors that children living with HIV/AIDS in *Kolfe* sub-city of Addis Ababa were using thrive the psychosocial experience that they faced in their communities such as at home, community and schools and preparing for their future. In order to carry out this qualitative research, a phenomenological approach with purposive sampling technique

applied. The ecological theory of Bronfenbrenner (1979) was employed in this study as a broad conceptual framework.

1.4. Operational Definition of Terms

Child refers to a person who is under 18 years of age, but for the purpose of this study between 10 – 18 years of age (MYSC 2004 in Moges Jemaneh[1], 2010). The terms child and adolescent are used interchangeably in this study since the main target of this research has been children between 10-18 years who are considered adolescents.

Psychosocial describes the relationship between psychological (understanding, attitude and beliefs an individual has) and social aspects of well-being, each interacting and influencing the other. It is the close connection between psychological aspects of experience (thoughts and emotions) and the wider social experience (relationships, practices, traditions and culture), both of which interact to form the human experience (CRS, 2009; SADC, 2011).

Psychosocial care and support is a support based on the psychological and social problems of children living with HIV, their caregivers, and families (WHO, 2010). It is an ongoing process of meeting the emotional, social, mental, and spiritual needs, all of which are considered essential elements of a meaningful and positive human development. It goes beyond meeting children's physical needs (CRS, 2009). Richter et al. (2006) described in detail that it psychosocial care and support is provided through interpersonal interactions that occur in caring relationships in everyday life, at home, school and in the community. This includes the love and protection that children

[1]In accordance with the Ethiopian custom, the first name or given names is substituted for the sure name and the father’s name and grandfather’s name are spelled out in full.

experience in family environments, as well as interventions that assist children and families in coping. Care and support enable children to have a sense of self-worth and belonging and are essential for children to learn, to develop life skills, to participate in society and to have faith for the future.

1.5. Objectives

The aim of the study was to explore the experiences of HIV positive children and to understand about what resources they have that make some of them thrive the day –to – day psychosocial life situations in *kolfe Keraniyo* sub-city of Addis Ababa. Specifically the study focused on gaining understanding:

- ✓ The positive factors that contribute to the psychosocial well-being of a child living with HIV in his/her environment;
- ✓ The coping mechanisms that are adopted by the children in order to address stigma associated with living with HIV/AIDS; and
- ✓ Life situations of children living with HIV and AIDS before and after being disclosed own HIV status.

1.6. Significance of the study

The research has aimed to explore the experiences of HIV positive children and to gain knowledge about what resources they have that makes some of them thrive the psychosocial life situations in *kolfe Keraniyo* sub-city of Addis Ababa. Beyond its academic purpose, I hope that this study has its own contributions in raising the psychosocial issues of HIV positive children in Addis Ababa. This could be achieved, for example, by presenting the results of the research to the service providers, advocacy

groups and policy makers in order for them to understand and take appropriate action to solve the problems of these children.

1.7. Limitation of the Study

Time constraints were apparent from respondents that were requested to spend a big share of their time for interview and group discussion, which clashed with their personal and household responsibilities and priorities. Nevertheless, to address this problem meeting times for the interviews had been arranged in their leisure time, mostly on Sundays and after 5:00 PM on weekdays. The other limitation seen in this study was that since none of the participant children living with HIV and AIDS has disclosed their status to school communities, neighbors and peers, it was challenging to assess and show the psychosocial experiences of these children in those social institutions.

There were also apparent limitations emanating from the very nature of the research method, i.e., the small sample drawn from limited area with a purposive sampling method. The total number of research participants was not intended to show a universal societal reality and way of life as generalizations to the broader population cannot be made from this research. All the participants are persons in their own right rather than representatives of all the children living with HIV in the country. However, it is possible to infer that the depth of exploration and flexibility that the method allows balances this problem of a small number of research participants. However, the stories of the children in this study give rich information in terms of life experiences and choices made by the different children.

1.8. Organization of the paper

The whole body of this thesis is organized as follows: the background to the present study, the research problem and question pertaining to the study, and the rationale behind the research and its limitations were discussed in the first chapter. The second chapter specifically looked literatures, concepts and review of the impacts of HIV/AIDS on children living with HIV/AIDS and the social support mechanisms that existed in response to ensure the wellbeing of these children.

In the third chapter, a detailed description of the research design and research procedures, the data collection process, the instruments used and their translations were verified. Chapter four presented the analysis of the data that had been collected using qualitative approaches. The last chapter highlighted conclusions drawn from embarking on the study and recommendations for further research.

Chapter Two: Literature Review and Theoretical Framework

This chapter encompasses three major sections: the first section reviews literatures in relation to the psychosocial impact of HIV and AIDS on children living with the epidemic. The second and third sections of this chapter describe about conceptual definitions and theoretical framework, respectively.

2.1. Literature Review

The literature review is heavily give attention to reviewing literatures related to the main sited HIV-specific challenges to psychosocial well-being of children living with HIV epidemic. These include disclosure of children's HIV-status, stigma and related discrimination, and psychosocial support. At the beginning of this sub-section an overview of literatures on disclosure of children's HIV status and children disclosing their own status were carried out. After that an overview of literature on HIV-related stigma was done before HIV-related psychosocial support literatures were consulted. Finally, the literatures carried out in Ethiopia in association with the above main topics were overviewed.

2.1.1. Literature on disclosure of children's HIV statues

The definition of disclosure refers to a child gaining knowledge of his/her HIV status (CRS, 2009) and/or a child's disclosure of their own HIV status to others (CRS, 2009; WHO, 2011). For the purposes of this review, the study focused on these types of disclosure. There are different issues in disclosing children's HIV- positive status for parents and children, but stigma and discrimination also play an important role in determining the process and effects of the disclosure. Literatures identify that parents

very frequently justify not telling their children of their (the children's) own HIV-positive status due to expected stigma and discrimination, and the children in turn disclose to others (Deacon and Stephney, 2007), guilt over prenatal transmission and the child is too young to understand (Hejoaka, 2009). In addition to parents keeping the secret of their children's HIV-positive status disclosure, various studies have pointed to children's reluctance to disclose to their HIV status to their peers, even when children do know their status (Deacon and Stephney, 2007).

Literatures suggest that disclosure of HIV status to children and adolescent has a positive impact on their lives as compared to keeping their status a secret (Amzel et al. 2013; Sibhatu et al., 2011; Cluver et al, 2012; Sherr, 2005). Potential benefits include improve access and maintain adherence to available treatment regimen (Bikaako-Kajura et al., 2006; Blasini et al., 2008), preventing HIV transmission, better access to social support and services (Deacon and Stephney, 2007), increased self-esteem among peers, and also ease parenting jobs in terms of social, material, and emotional support (CRS, 2009). Furthermore, family-centered disclosure builds trust in relationships and improves healthy communications between parents and children and disclosing of HIV status enables children and caregivers to cope better with HIV and adjust psychologically to live with HIV (CRS, 2009). For adolescents it also helps them to make informed decisions when contemplating sexual intercourse with a partner and encourage them to work towards reducing stigma, discrimination, and misconceptions and myths regarding HIV (Blasini et al., 2008).

In contrast to the above benefits of HIV status disclosure among children, literatures explore the existence of few possible negative effects of disclosure when

children know their status. These include initial emotional reactions such as getting upset, feeling sad and angry, and symptoms of anxiety during the first week after disclosure (Bikaako-Kajura et al., 2006; Blasini et al. 2008). However, these feelings have been reported to gradually replace with calm, relief, and comfort in understanding their condition, reasons for medication-taking, and satisfaction with the ability to openly ask questions and participate in their own care (Bikaako-Kajura et al., 2006; Vaz et al., 2011).

Even if studies support that family-centered disclosure builds trust in relationships and improves healthy communication between parents and children (CRS,2009), too often many HIV infected children and their families live in a 'conspiracy of silence' as fear of withdrawn, shame associated with AIDS, social isolation and emotional cut off from traditional support systems (Sherr, 2005). The most common disclosing 'barriers' identified in various studies include social rejection and isolation if the children tell anyone, guilt over prenatal transmission (Hejoaka, 2009), caregiver's lack of knowledge about HIV (Bikaako-Kajura et al., 2006), fear of negative psychological impacts for the children (Butler and et al., 2009) and disclosure is emotionally and psychologically challenging for the caregiver (Bikaako-Kajura et al., 2006). Various studies have pointed that due to high levels of expected peer stigmatization even when children do know their HIV status they are reluctant or lack of readiness and willingness (Kanesathasan et al., 2011) to disclose their HIV status to their peers (Deacon and Stephney, 2007).

Moreover, some studies identified other factors outside of stigma and discrimination such as health condition and home situation that determine the optimal disclosure process for the child. This may involve a long period of partial disclosure—

where the child is given information (e.g., about taking medicine, preventive message, etc.), but is not told that he or she is living with HIV—leading to full disclosure when the child is mature enough to understand the information (Amzel et al., 2013). In their psychosocial intervention project evaluation in Uganda Kanesathasan and his colleagues sorted out different barriers of disclosure including low assessment of caregiver readiness, poor assessment of child readiness, limited discussion or weighing of pros and cons of disclosure, and limited counseling support and disclosure tools/plans, limitations in communication, including between providers and caregivers (e.g., little counseling support for the caregivers, limited support to caregivers on how and when to disclose to the child), with the child (e.g., lack of provider and caregiver skills in how to communicate with children, limited guidelines on content of discussions with children), and insufficient capacity building in children so that they know when and how to share information about their status with others as needed (e.g., with peers, relatives, and teachers) (Kanesathasan et al., 2011).

Literatures also identified challenges that children and their caregivers can face in association with keeping the HIV epidemic illness undisclosed. For example, Abadia-Barrero et al. (2006) explain that keeping children's HIV status a secret from them can contribute to confusion resulting from unclear messages (CRS, 2009), compromised disease knowledge and an increased vulnerability to risk behavior (Bikaako-Kajura et al, 2006). Besides to this the CRS(2009) training manual identified depression, high development of self-stigma due to looking sick, refusal to take drugs, loss of confidence and trust in parents or mistrust(Bikaako-Kajura et al, 2006) , and poor child parent relationship, communication were some of the disadvantages of non-disclosure of HIV-

status among infected children. A study made in South Africa and Uganda show that nondisclosure may leave a child feeling isolated, and bring about accidental disclosure in an unsupported environment (McCleary-Sills et al., 2013).

The issue of disclosing children's HIV status has been discussed in the literature since the epidemic is affecting the world population a growing body of evidence is pointing to positive impacts of telling children the truth about their HIV diagnosis, the level of disclosure remains low (Amzel et al., 2013; Deacon and Stephney, 2007). Literatures on children's disclosing of own HIV status to others is rare in the Sub-Saharan setting. Those available few researches describe low status of HIV disclosure among children and disclosure in SSA still requires different considerations due to the different cultures and social constructions (Vaz et al., 2010). Studies from the Democratic Republic of Congo (Brown et al., 2011; Valz et al., 2011), Ethiopia (Abebe and Teferra, 2012; Biadigilign et al., 2011; Valz et al., 2011), and Kenya (Turissini, 2013; Valz et al., 2011) show that rates of disclosure to children are low, with all studies showing disclosure rates of less than 20 percent.

To sum up, the literature on disclosure has clearly indicated that it is a problem for children affected by HIV/AIDS and their caregivers. Barriers to disclose HIV status among young children are perceived at individual, caregiver, socio-cultural and health care settings. Stigma, discrimination and expected stigma and discrimination play a major role in influencing children's decision-making on, the impact of disclosure of HIV status. Low rates of disclosure impede children's access to support and services.

2.1.2. Literature on stigma

The Joint United Nations Program on HIV and AIDS (UNAIDS) has defined HIV related stigma and associated discrimination as "…a 'process of devaluation' of people either living with or associated with HIV and AIDS… and discrimination is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status" (UNAIDS, 2010:64). And in his broad definition of stigma Goffman (1963) stresses that stigma can not only be seen as a language of attributes, but also as a language of relationships, meaning that it is not only the attribute in itself that causes stigma, but rather the relationship between that attribute and what other people may ascribe to it(in Daniel, 2011). Literatures point out that stigma and discrimination associated with the HIV-epidemic is a major factor that distinguishes HIV/AIDS from other chronic or terminal illnesses (Amzel et al, 2013; Deacon and Stephney, 2007). Stigma and discrimination intensify the suffering of the disease and are major contributing factors to the secrecy related to HIV, resulting in many people living with HIV (PLHIV) keeping their status a secret (Letamo, 2004; Thupayagale-Tshweneagae, 2010). Furthermore, stigma is said to be one of the contributing factors to sustaining the epidemic due to secrecy and denial (Letamo, 2004). A literature reviewed by Mbonu et al (2009) shows that HIV and AIDS stigma is still highly present in SSA(Abebe and Teferra, 2012; Amare, Balcha and Solomon, 2013; Brown et al., 2011; Digsu et al., 2012).

Several literatures identify a number of contributing factors for stigmatization associated with HIV/AIDS epidemic including fear, ignorance, lack of basic knowledge and misconceptions about the disease (Abebe and Teferra, 2012; Amare, Balcha and Solomon, 2013; Daniel, 2011; Letamo, 2004; Thupayagale-Tshweneagae, 2010).

Misconceptions about HIV include believing one can get infected by sharing a meal, through witchcraft or a mosquito (CSA and ICF, 2011; Digsu et al. 2012; Letamo, 2004). Sherr(2005) also added that HIV/AIDS stigma may also be facilitated by the fact that the disease can be fatal, has no cure, and has noticeable physical effects during its advanced stages (Amzel et al,2013; Hejoaka, 2009; Thupayagale-Tshweneagae, 2010). HIV and AIDS stigma is in addition accompanied by other types of stigma, such as stigma related to poverty and family status (Abadía-Barrero and Castro, 2006; Vaz et al., 2010). This is important to note when dealing with HIV and AIDS stigma, since it is suggested that the majority of AIDS affected children live in poverty (Deacon and Stephney, 2007).

Different types of HIV and AIDS stigma are described in the literature, including stigma against those living with HIV and AIDS, internalized stigma, and stigma towards those affected by HIV and AIDS (secondary stigma) (Kanesathasan et al., 2011). Children and families affected by HIV face both external stigma—the negative attitudes and behaviors directed at them from outside people or groups (e.g., community members, schools, extended family, etc.)—as well as internal or self-stigmatization—the degree to which people living with HIV endorse the negative beliefs and feelings associated with HIV about themselves (CRS, 2009). Situations with children can be complicated by a caregiver's own experience with internal stigma, which limit how he or she is able to interact with and support the child (Kanesathasan et al. 2011). Effects of HIV and AIDS stigma include physical and social exclusion, gossiping, loss of identity, role or respect (Daniel, 2011). Stigma can also push caregivers to shield their children- parents do not tell their children that the children are living with HIV- because they're protecting their children (Deacon and Stephney 2007; Vaz et al. 2010). CRS (2009) also added while

stigma can be stereotyping, bias, distrust, labeling, or avoidance of someone in in association with HIV, discrimination is stigma in action or an act or behavior as a result of stigma.

Studies of children living with HIV have indicated that experiences of stigma and discrimination can lead to poor mental health, physical and social isolation, barriers to health and other critical services, as well as contribute to psychosocial distress, postponement of education, exclusion from religious organization, loss of identity, abuse, role or respect and reduced health-seeking behaviors (Vaz et al, 2010). HIV-related stigma plays a critical, sometimes unrecognized, role in the overall well-being of children living with HIV and their families. HIV/AIDS affected children experience stigma and discrimination related to HIV/AIDS related illness and death of their parents. Stigma may exacerbate the effects of bereavement and hinder children's psychosocial adjustment (Daniel, 2011; Deacon and Stephney, 2007).

Literatures show a number of negative effects of external and internalized stigma on the child, including lowering self-esteem and resiliency (coping with feelings of shame, blame, guilt, etc.); straining relations within family; reducing willingness to follow-through with care and treatment; and restricting social interactions, especially school; children can be good keepers of secrets, and as such, adults may underestimate what a child knows or experiences, or may think the child is coping well (Kanesathasan et al. 2011). As a consequence available information shows that HIV related stigma has enormous negative impact on social relationships, access to resources, social support network, and psychosocial well-being of PLWH. Prone to both stigma internalization and stigma associated with HIV-epidemic, HIV positive people are less likely to seek

social support for fear of rejection and isolation. Such stigmas can be manifested in many ways, from increased risk behaviors, to caregiver reluctance to access services, seek social supports for fear of rejection and disclose status/information, to family and community neglect of the child, to isolation and depression experienced by the child and/or caregiver. Besides to this the related stigma and discrimination hampers effective HIV prevention activities (condom use, HIV test seeking behavior, care seeking behavior) and is a barrier to diagnosis, quality of care provided to HIV positive patients, and the perception and treatment of PLWH by communities, families and partners(Kanesathasan et al., 2011; UNAIDS, 2008).

Literature also identified that children use different coping mechanisms to handle stigma. Some use disclosing of one's status to seek support, at the same time as non-disclosure is also seen as a coping mechanism in order to protect oneself, spending time with other HIV positive people, engaging in HIV and AIDS education, or turning to religion for comfort (Vaz and et al. 2010). There are also possible factors associated with decreasing levels of social stigma including increased knowledge about HIV (Abadía-Barrero and Castro, 2006; Vaz et al. 2010), and peer influence (frequency of discussing HIV and AIDS with friends) (Bikaako-Kajura et al. 2006). It has furthermore been found that in an African setting family members, teachers and elders have more influence on young children regarding dispelling myths about HIV and AIDS and in being sources of useful information, compared to the mass media (Abadía-Barrero and Castro, 2006; Deacon and Stephney, 2007). Another important factor in reducing stigma is the availability of ART. Studies from Botswana and Brazil suggest that access to ART is associated with lower levels of perceived stigma towards oneself and holding

stigmatizing attitudes toward others (Daniel, 2011; Vaz and et al. 2010). This finding is related to ART transforming AIDS from a fatal to a chronic and manageable condition, which results in a change in the way people perceive the disease (Abadía-Barrero and Castro, 2006). The availability of ART has helped individuals with advanced HIV and AIDS symptoms in diminishing their visible symptoms of disease, enabling them to return to socially and financially productive lives. This contributes to a higher rate of testing for HIV and willingness to initiate HIV treatment (Sherr, 2005; Deacon and Stephney, 2007).

Summing up the literature on stigma and discrimination, it is evident that stigmatization of children living with HIV and AIDS further complicates living with a serious disease, and makes prevention and treatment efforts challenging. A limited number of studies have focused on what resources HIV positive children in SSA use to cope with stigma, during this study I will investigate further what some of these resources could be.

2.1.3. Psychosocial support

The World Health Organization (2010) defines psychosocial support (PSS) as support based on the psychological and social problems of people living with HIV, their caregivers, and families. Similarly, SADC (2011:19) refers it to a "continuum of care and support that addresses the social, emotional, spiritual and psychological needs" of people living with HIV, all of which are considered essential elements of meaningful and positive human development, and influences both the individual and the social environment in which people live (REPSSI, 2008; Richter et al., 2006).

All children and adolescents require unconditional affection, protection and nurture that families and the community usually provide. When they grow, children require friendships with same-aged peers and to be members of social and cultural associations including educational, play, social and/or religious groups. This sociality helps children acquire the behavior and moral values expected of people in their society and equips children to become full participants in their communities (Richter et al, 2006). Meanwhile little research attention has been done on the psychosocial aspects of the lives of children infected by HIV/AIDS (Culvet et al. 2012; Daniel, 2011; Deacon and Stephney, 2007).

Because of the above mentioned (Section 2.1.1-2) and other psychosocial challenges facing these children living with HIV/AIDS together with the pain and distress of chronic illness of the HIV-epidemic, both children and their caregivers need social support in order to become happy, creative, and to belong into social groups, and to have hope for the future(Sherr, 2005). For these children, Gilborn et al.(2006) added that HIV is a chronic disease requiring a lifetime of continuous treatment, care, and support to ensure their physical and mental development, social relationships, access to resources, social support network as well as their emotional and psychological well-being of children living with HIV. Studies indicate that these outcomes possibly come into practice through the application of psychosocial support. Besides to the healing of psychosocial problems some studies considers it as provision of unmet children's right to develop to their full potential (Richter et al., 2006).

Literatures suggest various issues about the importance of PSS for children living with HIV and AIDS. An ongoing psychosocial support has a number of advantages for

these children including gain confidence in themselves and their skills, deal more effectively with stigma and discrimination, taking medications every day, and caring for an HIV-exposed or HIV-infected child(CRS, 2009). It also help them to mitigate the effects of trauma, to make informed decisions, cope better with chronic illness, and improve the quality of their lives (Culvet et al., 2012). Regional Psychosocial Support Initiative [REPSSI] (2008), an institution extensively works on PSS for OVCs in Southern and Eastern Africa, strongly suggests that PSS is especially critical for children, creating the foundation from which they can establish their identity and place in society, manage their care and live positively, cope with challenges, and plan for their future (Gilborn et al. 2006; Mavhu et al., 2013). The literature shows that PSS also supports families and caregivers to meet the multiple needs that children have, provides parents with inter-personal acceptance, opportunities to exchange valuable information, goods and services (REPSSI 2008). Basic and ongoing supports from those within the child's sphere (e.g., family, relatives, friends, teachers, etc.) play an essential role in ensuring emotional development as the child matures (Amzel et al., 2013; Gilborn et al., 2006). The psychosocial well-being of children and their caregivers can also improve adherence to ART and clinical outcomes (Gilborn et al., 2006; Kanesathasan et al., 2011; Richter et al., 2006).

Available literatures explain that it is difficult to identify a single model for providing PSS since it depends on the specific situation of the child, the local context in which he or she lives, and the resources and networks available to support his or her care (Kanesathasan et al., 2011). However, Cluver et al. (2012) identified three broad categories of psychosocial interventions for school-aged children affected by HIV/AIDS:

those psychosocial interventions that are supported by evidence for their effectiveness, those popular interventions which lack sufficient evidence, and interventions that address proven mechanisms of psychosocial problems. The first group includes school-based peer group support, mentoring, and solution focused stories, and residential camps, broad-based psychosocial support programs, school-based activity groups and school strengthening, and community-based psychosocial support programs are categorized in the second group. Meanwhile providing ARVs to parents, prevention of parent-to-child transmission and provision of paediatric ART, reducing AIDS-related stigma and bullying, anti-bullying, increasing social support and caregiver/child connectedness, reducing poverty, and home-and community-based care are in the third group.

REPSSI stresses a continuum of care and support offered by caregivers, family members, friends, neighbors, teachers, health workers, and community members on a daily basis to nurture the psychological and social aspects of a child's development (REPSSI, 2008; SADC, 2011). PSS is the process of meeting a child's emotional, mental, spiritual, and social needs through a variety of approaches, such as one-on-one counseling, support groups, and play therapy and social support that can help people and their careers to cope more effectively with each stage of the infection and enhances quality of life (Kanesathasan et al., 2011; Richter et al., 2006).

Several studies identify broad sources and types of psychosocial supports that address psychosocial needs of children living with HIV. Literature broadly categorize the sources of social support in to two—formal and informal (George, et al., 2009). The former consists of professional support systems (health care and social service providers like HIV-related organizations) and the latter of family, friends, and other community

organizations (such as churches, schools)(George et al.2009; SADC, 2011). In managing most chronic diseases (including HIV), informal social support networks, particularly kin, are acknowledged as critical sources of social support. The community has also an important role to playing assisting PLWHA through provision of economic, social and psychological supports (SADC, 2011).

The types of social support are emotional, instrumental, informational and appraisal support (also affiliative support and social-integration) (George et al. 2009; Richter et al., 2006). Emotional support is understood as non-tangible help from members of an individuals' social network that leads to a person feeling loved and cared for, empathy, affection, listening and with a bolstered sense of self-worth (e.g., talking over a problem, providing encouragement/ positive feedback). Instrumental support is understood as various types of tangible assistance in the form of financial aid, material goods, labor, time, or any direct help. Informational support is a third type of social support and is understood as the help that others offered by providing information (e.g., information about medication, treatment options, nutrition, housing, food banks, legal aid). Informal social support networks or families and friends supports, particularly kin, are acknowledged as critical sources of social support (CRS, 2009; Gilborn et al., 2006). The appraisal support involves the number of social relationships an individual has with others that have mutual interests. For some HIV-positive people, availability of support from family members improved odds of entry into medical care, regardless of whether the person was already receiving (or not receiving) support from ancillary HIV services(George et al, 2009).

Studies also show that effectiveness of PSS necessarily depends on caregivers, service providers, and other adults around the child to provide a range of ongoing care and support (Kanesathasan et al., 2011). Given the importance of PSS to the long-term well-being of children living with HIV, there is a critical need to ensure that continuous and individualized psychological and social services are fully integrated within a broad, integrated framework of care provided by parents/caregivers, and service providers (facility, community, and home-based) and adapted over time as children develop and mature (Kanesathasan et al., 2011; REPSSI, 2008; Richter et al., 2006).

To sum up the literatures of psychosocial support for children living with HIV and AIDS and their caregivers, given its complex and multidimensional nature, psychosocial wellbeing requires support for individuals and families as well as a supportive community environment. Children can get the psychosocial support in various forms, including one-to-one counseling sessions, caregiver support and training, support groups for children-caregiver dyads, peer/mentorship from youth living with HIV, and recreational therapy developed to tackle AIDS-related social and psychosocial challenges, and those supports can be provided by healthcare providers, peer counselors, mentors, OVC programs, and community support groups. It also helps the prevention of HIV in the next generation and the long-term advancement of society. Various studies have focused on what mechanisms HIV positive children in SSA get to prepare themselves for future, during this study I will investigate further what some of these resources could be.

2.1.4. Literatures about children living with HIV/AIDS in Ethiopia

In Ethiopia the psychosocial experiences of vulnerable and AIDS orphaned children (OVC) have been explored in several studies (CRDA, 2006; FSCE, 2006; Hiwot, Fentie, Lakew, Ababe and Wondosen, 2011; Kedija, 2006). However, recently only little journals and pre-and post- project intervention assessments and evaluations have been done on the psychosocial aspects of the lives of children infected by HIV/AIDS (Amare, Balcha and Solomon, 2013; Sibhatu et al. 2011; Garumm et al. 2012; FHAPCO, 2012; Digsu, 2012; Jani, Nrupa and Schenk, 2014).

The available information confirms that the above-mentioned psychosocial problems (Section 2.1.1-3) of children living with the HIV pandemic remain significant challenges in Ethiopia. For example, in the national HIV-program progress report the federal HAPCO (2012) indicates that disclosure of HIV status to children remains a complex and a critical clinical issue in the care of HIV infected children. Amare et al. (2013) suggest the prevalence rate of HIV-status disclosure among children living with HIV receiving ART in the country is lower(31.5%) as compared to studies done in high-income countries in which the disclosure rate ranges from 35 to 90 percent in the USA and Europe (Digsu et al., 2012). The lower prevalence of disclosure they assume, is due to fear of stigma and discrimination by the family members, and caregiver's perceived lack of emotional preparedness of the children and if the child is told he/she will reveal to others leading to stigma and discrimination to the family(Amare et al., 2013; Digsu et al. 2012). Jani, et al. (2014) support the presence of stigma and discrimination against people living with HIV and AIDS in Addis Ababa. They describe that stigma exists not

only at the societal level, but also within households. In order to cope with these challenges people do not want healthcare staff visiting them in their homes for fear that neighbors will suspect their status, and intentionally attend health clinics that are far from their homes where they will not see neighbors or be visited by health staff. Poor living conditions and poverty can also increase the likelihood of experiencing adverse conditions such as psychological distresses among children living with HIV and their caregivers.

The main factors associated with HIV-positive status disclosure for children include caregiver's relation with the child, age of the child, loss of a family member, caregivers' and healthcare staffs' lack of knowledge and skills (Amare et al., 2013), and lack of guideline for disclosure of children with HIV/AIDS (Digsu et al. 2012). Accordingly, literatures suggest appropriate psychosocial care and support that enhance children's, families', and communities' ability to cope in their own context are essential in order for children to learn, develop life skills, participate fully in their community, and have faith for the future.

In response to the multidimensional impact of HIV/AIDS the government of Ethiopia together with other national and international organizations, civil societies, faith based organizations and associations has been undertaking various prevention, control and care and support activities. The government has largely prepared and approved various policies, plan of actions, guidelines and legal frameworks that provide enabling environments for the prevention and mitigation of HIV/AIDS as well as to protect those groups affected by the epidemic. For example, in the Federal Constitution the right of children in general and vulnerable children in particular is articulated in Article 36 sub-

article 5. In addition to this Ethiopia has ratified both the UN Child Right Convention (CRC) and the African Charter on Rights and Welfare of Child (ACRWC) international legal instruments that protect the rights of children (FHAPCO and MOWA, 2011). Furthermore, a number of guidelines representing significant initiatives towards creating a supportive environment for the OVC have been put in place. These include the guidelines for alternative childcare programs; the national strategic framework for HIV/AIDS; the national guidelines on care and support for PLWHAS and OVC; the clinical guidelines for children infected by HIV/AIDS; and standard service guidelines for OVC care and support programs. These legal and policy frameworks enable the involvement of NGOs, UN agencies, INGOs, FBOs and CBOs in the provision of various care and support services to OVC (MOWA and FHAPCO, 2011).

Available information indicated that there were 800 HIV/AIDS related service providers in the ten sub-cities of Addis Ababa, including non-governmental organizations(NGO), community based organizations(CBO), Health Facilities, faith based organizations(FBO) in Addis Ababa(*Timret Lehiwot* service provider directory, 2014). Those service providers have taken the initiative to provide care and support services through the home and community based approach as well as information, and services share through referral linkages. These organizations rendered services to OVC at community grassroots in the following six focused areas:

- Educational support such as school uniforms, school fees, tutorial support, non-formal education, school feeding programs and school materials;
- Early childhood development including clothing, feeding, sanitation, nursery schooling and day care service;

- Psychosocial support such as counseling, home visits, recreational support, peer education, life skill training, succession planning and family reunification;
- Health support programs which provide services such as medicine, HIV/AIDS prevention education, hygiene and sanitation, adolescence reproductive health information, vaccination, VCT and ART;
- Food support such as supplementary food, food rations (safety net) and financial support;
- Livelihood support including income generating activities (provision of startup capital), vocational skill training (apprenticeship), agricultural and subsistence financial support (FHAPCO, 2012; MOWA and FHAPCO, 2010).

There is no recent study regarding the types of services and child inclusion criteria of NGOs, CBOs, FBOs, etc. in Ethiopia in general and in Addis Ababa in Particular. However, based on the 2007 report of ministry of justice(MOJ) more than three quarters (78%) of children-focused NGOs were engaged in education, psychosocial, and health related support while about two thirds (66%) of children-focused NGOs were engaged in interventions including advocacy and awareness raising, food support as well as livelihood related interventions. Only one third of organizations were involved in childhood development intervention programs (MoJ, 2007:34).

In Ethiopia, the psychosocial support (PSS) for HIV positive children and adults has been mainly run through a number of organizations including faith based organizations, local and international organizations, charities and associations. However, the majority of those organizations provide PSS to vulnerable children more generally rather than HIV positive children specifically.

To sum up – the children-focused organizations have made considerable efforts to promote the psychosocial-wellbeing of children living with HIV by providing support such as education, psychosocial assistance, healthcare, food and nutrition and early childhood development care in their respective operational areas at community grassroots. Despite such considerable efforts, the provision of psychosocial support is not specific to those children living with HIV. Furthermore, there have been apparent limitations among children-focused NGOs that insufficient budget allocation to meet the needs of these children. Besides, Ethiopia has plenty of laws, guidelines and policies regarding children on paper. Ethiopia is the first to adopt and sign international laws, but the problem is the enforcement of laws and policies. Most of the adopted laws and formulated policies do not have strategies and guidelines for how they are implemented, and those which have the strategies and guidelines are not implemented to address the intended objectives.

2.2. Conceptual Definitions

2.2.1. Child

The concept child is central to this specific study because the main target group falls under the category of 'children'. There is no internationally agreed single definition that describes this group of human beings. For example, UNICEF and UNAIDS initially defined children as those groups of human being age 15 and bellow, but in order to come to the child right convention (CRC), it was raised to 18 years and under (UNAIDS, 2004; Deacon and Stephney, 2007: 9). The African Charter on the Right and Welfare of a Child (ACRWC) developed by the African Union in 1999 also adopted the definition of childhood include up to the age of 18. The most widely used definition currently is the one which is adopted by the UN for the formulation of the CRC and it is used as an official standard definition throughout the world.

It defines child as 'every human being below the age of 18 years unless, under the law applicable, majority is attained earlier' (UN 1998, Article 1). When using this definition it does not mean that it will apply to all communities in the world in the same way, but as it is accepted by many nations in the world, it will have a significant implication on policies and intervention strategies that focus on children. The definition of child is socially constructed and therefore its meaning varies from one society to another at different times in history. In the constitution of the Federal Democratic Republic of Ethiopia (FDRE), a child is defined as any person below the age of 18 years, consistent with the UN Convention on the Rights of the Child. The same definition is adopted in this study. Besides, for the purpose of this study, children are those human beings belong to 10 to 18 years.

2.2.2. HIV infected Child

HIV infected Children is defined as a child - whatever the transmission might be "who has had antibodies against HIV detected on a blood or saliva test or at birth through a test to detect the HIV virus itself and the child might live in HIV-positive or negative households" (UNAIDS, 2012: 8). UNICEF (2011:6) associated the definition with the impact of HIV and AIDS and defines as those individual boys and girls whose wellbeing or development is threatened by HIV as they live with HIV and in HIV-affected households and communities. Literatures suggest four possible methods that children become infected with HIV: mother –to –child transmission, sexual transmission, inject drugs, and blood transfusion (http://www.avert.org/children-and-hiv-aids.htm). The early literature describes two patterns of illness progression for children with HIV: those who become ill with opportunistic infections early in life and have a poor prognosis, and those who remain relatively well. Prematurity has been linked to shorter survival in positive infants. In the absence of treatment, this pattern still prevails (Sherr, 2005). CRS (2009) also mentioned some effects of HIV on the development of children living with HIV. For example, 20 -40% of children perinatally infected with HIV face problem of brain development; early occurrence of neurological impairments; and significant learning problems that affects their ability to function in school, develop friendships, and function independently.

2.2.3. HIV/AIDS

Conceptualizing about HIV/AIDS is equally important in this particular study as it focuses on the impacts of HIV on children 10 to 18 years living with the epidemic in their

social and psychological (psychosocial) aspects of their lives. The term AIDS applies to the most advanced stages of HIV infection (UNAIDS, 2012:6).

Mann (1976) quoted in Moges Jemaneh (2010:13) categorized three stages of the HIV/AIDS epidemic: the epidemic of HIV, the epidemic of AIDS, and the epidemic of stigma, discrimination and denial. While the first two phases are related to the biological nature of the disease, the last phase is related to be the social paradigms given for the disease. The social construction of the epidemic is associated with stigma, exclusion, repression and discrimination their communities in different settings (Deacon and Stephney, 2007) have rejected discrimination as people with HIV/AIDS and their families. Given aside for the moment other assumptions and constructs to the diseases people with HIV/AIDS are often 'culturally' believed to have deserved what has happened by doing something wrong. These include having homosexual or as having had sex with prostitutes for men and as having been 'promiscuous' or as having been sex workers for women (CRS, 2009; CSA and IFC, 2011; WHO, 2011).

The social speculations associated with HIV/AIDS have powerful psychosocial consequences for people living with HIV/AIDS, especially children and youth who live longer and also challenging with human development stages (Amzel et al, 2013). The speculations also undermine prevention and mitigation efforts to limit the progression of HIV and to mitigate the impact of the AIDS epidemic by making people, for example, afraid to find out whether or not they are infected, for fear of the reactions of others(CRS, 2009; Deacon and Stephney, 2007;Sherr, 2005). These misconceptions cause people with HIV/AIDS to be seen as some kind of 'problem', rather than part of the solution to contain and manage the epidemic (Moges, 2010:15).

To sum up – the wrong speculations stated above and other social speculations associated with HIV/AIDS have two broad social effects. First, because the social speculations about HIV/AIDS is associated with marginalized behavior and groups, all individuals with HIV/AIDS are assumed to be from marginalized groups and some may be stigmatized in a way that they were not before. Second, such social speculations associated with HIV/AIDS exacerbates the stigmatization of individuals and groups who are already oppressed and marginalized, which increases their vulnerability to HIV, and which in turn causes them to be further stigmatized and marginalized.

2.2.4. Thriving

Expressions such as 'thriving' and 'resilience' are well known within the social-psychology literature. Carver (1998) explains the concept of thriving as benefitting from adversity (serious physical or psychological stress or trauma). He suggested that after a physical or psychological downturn, there are four possible outcomes: succumbing, survival with impairment, resilience (recovery) or thriving which Carver refers to as "the person may not merely return to the previous level of functioning but may surpass it in some manner" (Carver, 1998:245). These concepts imply that the person must have experienced adversity in order to show resilience or thrive.

2.1.5. Psychosocial Support

Psychosocial support defined by the World Health Organization (2011) is support based on the psychological and social problems of people living with HIV, their caregivers, and families. According to SADC (2011:19) it refers to a "continuum of care and support that addresses the social, emotional, spiritual and psychological needs", all of

which are considered essential elements of meaningful and positive human development, and influences both the individual and the social environment in which people live (REPSSI,2008; WHO, 2011). Richter et al.(2006) explain social support as the love and protection that children experience in family environments, community as well as interventions that assist children and families in coping challenges and provided through interpersonal interactions that occur in caring relationships in everyday life, at home, school and in the community (SADC, 2011; WHO, 2009). Daniel (2011: 145) added to that social support as the perception that one is "loved and cared for by others esteemed and valued, and part of a social network of mutual assistance and obligations".

In Daniel (2011), social support is associated with improvement in access and adherence to ART, medication uptake, retention in care, physical functioning, body weight of PLWHA, and mortality. The concept of social support has also been associated with the following: improvements in psychosocial functioning; stronger self-esteem, rates of serostatus disclosure, self-efficacy, family functioning, active coping, and health outlook. Lastly, research suggests social support may lead to reductions in HIV-related stigmatization, psychiatric disorders, depression, psychological distress, and avoidant coping (Amzel et al., 2013).

Appropriate psychosocial support enhances children's, families', and communities' ability to cope, and to achieve personal and social well-being. It enables children to have a sense of self-worth and belonging and are essential for children to learn, to develop life skills, to participate in society and to have faith for the future (REPSSI, 2008; Richter et al., 2006; SADC, 2011; WHO, 2009). PSS is especially critical for children, creating the foundation from which they can establish their identity

and place in society, manage their care and live positively, cope with challenges, and plan for their future (Gilborn et al., 2006; Mavhu et al., 2013).

Attempts have been made to distinguish between ‘psychosocial care’, ‘social support’, and/ or ‘psychosocial support’. In different countries, the terms ‘care’ and ‘support’ have different meanings. For this document, ‘psychosocial support’ or ‘social support’ is used for ‘psychosocial care and support’.

2.3. Theoretical Framework

It is evident that HIV/AIDS has become a severe threat to children’s growth and development in many ways. Besides to the frequent illness and hospitalization, the stigma associated with HIV often leads to the withdrawal of family members, and peer related isolation as a result of misconceptions regarding viral transmission. Additional noted stressors associated with HIV among this population include disclosure of HIV infection, fears of death, family conflict, access to health care, medication regimens, and repeated hospitalization (Richter et al., 2007). This is particularly sever in SSA countries where most children lost their parents which made them vulnerable to child labour and lack of access to health and education(Richter et al., 2006). Hence, literatures indicate that HIV positive children and adolescents are not only at an increased risk for adjustment difficulties resulting from the symptoms and management of a chronic illness, but also from the specific environmental stressors commonly found among this population (Amzel et al., 2013).

The epidemic therefore has insurmountable effects on the normal growth and development of children. This section specifically gives emphasis on ecological system theory that was applied as a broad conceptual framework to explore the positive

resources that contribute for children living with HIV to thrive the psychosocial experiences they face in their home, school and community and preparing for their future life. The ecological theory outlines how the combination of one's surroundings all play a role in child development and health, in particular as theorized by Urie Bronfenbrenner.

2.3.1. Bronfenbrenner's Ecological Systems Theory

Urie Bronfenbrenner's Ecological Systems Theory of Human Development (1979) examines the child development in multiple social and physical surroundings during adolescent development (Hosek, Harper, Lemos, and Martinez, 2008). The ecological systems theory explains how everything in a child and the child's environment affects how a child grows and develops. Bronfenbrenner(1979) suggested that in order to understand child development, the entire ecological system in which growth occurs needs to be taken into account. The model specifically developed to further the understanding of risk and protective factors associated with children's psychosocial health and sees children at the center of multiple, interacting layers of influence (Cluver et al., 2012).

Different literatures suggest the importance of this ecological theory. For instance, SADC (2011) suggested that Bronfenbrenner's theory is advantageous to explore community-based psychosocial interventions for OVCs as well as for field practice, research, and it gives emphasis to the intra and inter contextual child development (Aldridge and Sexton, 1997). Thomas (1992) also argued that the theory looks at a child through the life span, unlike other psychosocial theories such as Erikson, instead of during early infancy and childhood and it gives due attention to an ongoing child, family, and community group (Thomas, 1992 in Thembela, 2007:27). Besides to

these advantages the theory has recently been adapted for use with AIDS-affected children (Amzel et al., 2013;Cluver, Kganaka, Boyes, and Park, 2012; Kanesathasan et al., 2011; Richter et al., 2006; SADC, 2011).

The ecological systems theory is composed of five socially organized subsystems that support and guide child's development, starting from people and institutions immediately surrounding the individual to nation-wide cultural forces. The five subsystems include the microsystem, the mesosystem, the exosystem, and the macrosystem, and the lately developed chronosystem (Swick and Williams, 2006).

Microsystem: is the most proximal layer closest to the child and it contains the structures with which the child has direct contact. The microsystem encompasses child's sex, illness, age, and the direct relationships and interactions a child has with his or her immediate surroundings such as family, school, neighborhood, or childcare environments. At this level, bi-directional influences are strongest and have the greatest impact on the child (Amzel et al., 2013; Cluver et al, 2012).

Mesosystem: These systems connect two or more of the child's microsystem in which child, parent and family live. For example, the connection between the child's teacher and its parents, healthcare giver and its parents, between his church and his neighborhood, each represent mesosystems (SADC, 2011).

Exosystem: this system defines the larger social system in which the child does not directly function. The child may not be directly involved at this level, but they do feel the positive or negative force involved with the interaction with their own system. The main exosystems that indirectly influence children through their family include school and peers, parents' workplace, extended family supports, hospital environment, school

environment and home environment, mass media, family social networks and neighborhood community contexts, local politics and industry (Hosek et al., 2008).

Macrosystem: is the other distal systems to the child includes the wider political, policy, and cultural factors that contribute to the contexts in which children live. Macrosystems can be used to describe the cultural or social context of various societal groups such as social classes, ethnic groups, religious affiliates, attitude towards childcare, health care financing priorities, general environment conditions, cultural or community beliefs about illness. This layer is the outermost layer in the child's environment as shown in the Figure 1 bellow (Cluver et al, 2012; Hosek et al, 2008).

Chronosystem: encompasses the dimension of time as it relates to a child's environment. Elements within this system can be either external, such as the timing of a parent's death, or internal, such as the physiological changes that occur with the aging of a child (Swick and Williams, 2006).

Based on the proximity to the children, the direct involvement of the children with components of systems, and the level of impact on the children's development, the following figure (Figure 1) tried to show the above literature explanations of systems.

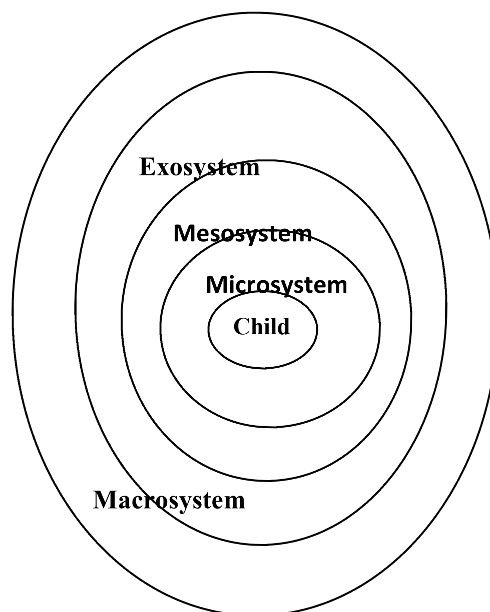

Figure1. Socio Ecological Theory Model

According to Bronfenbrenner (1979), these ecological systems are interactive and characterized by roles, relationships, and norms and the relationship and interactions between these structures change as a function of development. Each system depends on the contextual nature of the child's life and offers an ever-growing diversity of options and sources of growth. Furthermore, within and between each system are bi-directional influences. When the relation between different microsystems is compatible, development progresses smoothly (Bronfenbrenner, 1979, 1986 in Hosek et al, 2008). The theory suggests that the impact of severe adversity (such as living with HIV or belonging to an AIDS-affected family) in a particular ‘sphere’ of a child’s life can be mitigated by positive factors in another ‘sphere’ (Cluver et al, 2012).

To sum up this chapter - the central concepts and the theoretical approach of this study have been the two main issues reviewed in these sections. With the aim to

investigate the psychosocial experiences encountered by children living with HIV/AIDS, literatures were reviewed on HIV disclosure and stigma that are more psychosocial stressors against children infected by the epidemic and psychosocial support which is the necessary stress reducing mechanism. Besides to the review of literatures six important concepts have been explained: child, HIV/AIDS, HIV/AIDS infected children, thriving, psychosocial and psychosocial well-being, and psychosocial support. Pointless to say, obvious variations on the definition of each of these concepts still exist. Appreciating the existence of such variations, it is essential to provide concise contextual meanings for each of the concepts as it is applicable to the study. As a theoretical framework of the study, the Bronfenbrenner's ecological system theory on child development has been over-looked with an emphasis on children between 10-18 years of age. In order to assess the essential social settings that potentially bring changes in child psychosocial development as described by Bronfenbrenner, assumptions of the theory have been discussed. The researcher also argues that HIV/AIDS has become a forecaster threat to children's growth and development in many ways. The psychosocial effects associated with the HIV epidemic are undefeatable challenges to children living with HIV in poor community where stigma and discrimination is high. The environment plays a dominant role in the psychosocial well-being of children. The home serves as the basic environment in which the child's development is established and enhanced. A healthy atmosphere at home is required for the total development of the child. If the child's home environment is conducive, the child will be able to cope easily in other secondary environments such as school, church and the community. The different components of the environment, namely the home, school and community, play an important role in the

psychosocial well-being of children. In the next section, literatures were viewed about the psychosocial impacts of HIV/AIDS on children living with HIV together with the social support mechanisms available to assist these children.

Chapter Three: Research Methodology

3.1. Research Design

For this qualitative research, a phenomenological design was employed. A phenomenological approach facilitates the understanding of the lived experiences of the subject to seek a deeper explanation of a phenomenon. This requires in-depth study of the subjects, and the researchers own experiences and assumptions of the phenomena have to be put aside in order to fully capture the lived experiences of the subjects and how they perceive their reality (Creswell, 2007; Creswell and Thorogood, 2009). The purpose of this study is to gain understanding of the psychosocial experiences of HIV positive children ages between 10 -18 years old in *Kolfe keraniyo* sub-city, and to gain knowledge about resources that enable some of in these children thrive in spite of their challenging life situations.

3.2. Study Area and participants

Study Area: As mentioned before, this study was carried out in *Kolfe Keraniyo* sub-city of Addis Ababa city, the capital of Ethiopia. This sub-city is one of the ten Addis Ababa sub-cities with the largest population found in the North-Western part of Addis Ababa. According to the 2007 Population and Housing Census of Ethiopia *Kolfe Keraniyo* sub-city had a population of 428, 895 people where 207, 641were males and the remained 221, 254 were females (CSA Report, 2008) and the sub-city has 15 administration *Woredas (*districts). There are three government health centers and one hospital that are providing ART program in the 15 *Woredas* of sub-city and children in two districts located in one of the poorest suburbs of the city in which the large amount of affected

children resided and the hospital that serve the largest ART program were selected for this study. In order to protect the participants' identities, names of the study sites were not used.

Participants: in a phenomenological study the aim is to get in-depth information of a given phenomenon - the psychosocial experiences of HIV affected children in this research case – and this can be achieved through purposeful selection of participants (Creswell, 2007). This approach is used for this study, as far as possible, selecting participants that are likely to provide useful data about the issue.

Inclusion criteria were HIV positive children ages between 10 and 18 years old, those who know their HIV status and attending ART in government hospital and registered in the organization for care and support services. Besides, to examine the school environment, next to home and community, in relation to psychosocial experiences and support, these children living with HIV children who were enrolled were included.

The researcher together with the hospital nurse voluntarily chose the participants for focus groups discussion from some children who were taking ART in the hospital and the organization social workers at the study site identified the children for in-depth interview, after they informed about the study, its purposes and the inclusion criteria of the participants. The social workers knew the area very well, as they were living there for longer time. They visited the children and their caregivers who agreed to be part of the study in their homes to get the caregivers' permission for the involvement of their children in the study. The researcher did not take part in these first visits, in order to

respect the family's privacy, as they might not be comfortable with a stranger coming to their homes without being asked beforehand.

A total of 26 children (thirteen boys and thirteen girls) living with HIV ages between 10 to 16 years and three key staffs were involved in the study. The three key staffs were a nurse from health center, a social worker of the organization who worked directly with children and an officer from an organization working in the sub-city. This triangulate the information gathered about the children's psychosocial experiences support and the environment, and how people who work closely with the children understood the children's situation. Furthermore, for ethical reasons, children in a state of acute illness were not included in the study.

3.3. Sampling Techniques

Creswell (2007) explained that purposive sampling is used in qualitative research since the sites and researcher selects participants for study as they can purposefully inform an understanding of the research issue and central phenomenon in the study. The study employed a 'purposive sampling' method. The selections of these children for the focus group and face-to-face interviews were purposively taking different attributes like age and gender into account. With this in mind, the samples in the research were selected from both sexes within the age range of 10-18. In terms of economic status the research mainly focused on those who are found in the lower income level.

3.4. Data collection Procedures

To secure the consent of the organizations and the health center where the children were getting social and healthcare, and key informant staffs work, and Woreda Women,

children and youth affair's offices, letter of cooperation from Addis Ababa University was provided before conducting the interview and the focus group discussion. Two gender-specific focus groups were conducted with a total of 16 participants (8 female, 8male), and 10 individual interviews (5 male, 5 female) were completed. While the focus group took place in the health center, in-depth interviews took place in private home compound and were audiotaped. The focus groups and interviews were conducted in the local language, Amharic. A semi-structured questioner guided both the interview and the focus group discussion, which was identical for both focus groups and individual interviews, with suggested probes to elicit and clarify responses. The researcher of this study moderated the discussion and tape recorders were used. Staffs as key informants were interviewed in their respective office.

Data Collection

For this study the focus groups served as a tool in getting to know the participants, to get an idea of what the participants felt about certain themes, and as a tool in the process of selecting participants for the individual interviews. In order to avoid uncomfortable environment among girls and boys that might happen due to a mixed group discussion, two focus groups meetings were held at the hospital site, the first consisting of eight girls, and eight boys were involved in the second discussion.

Focus groups can capture a broad range of ideas concerning a given topic (Green and Thorogood, 2009), and it allows the adolescents to discuss together, they can respond to each-others ideas and it can be easier for them to talk when being with other children in the same situation. Observing this interaction can potentially provide even more understanding of a phenomenon. The setting of being in a group might feel more natural

compared to the in-depth interviews, inviting an honest discussion. In addition it can reduce power imbalance between the researcher and the subjects. However, peer pressure and the fear of being perceived as different by expressing different ideas and thoughts than the others, can be an issue within the age group chosen for this study. Also, in a group setting there will often be someone more dominant and talkative than others, who can end up talking on behalf of the rest of the group. Trying to overcome this, ground rules were made at the beginning of each focus group, trying to facilitate emotional 'safety', an environment where it feels 'safe' to speak, this can encourage the participants to express their honest thoughts.

The focus groups began with casual talk, where everybody introduced themselves with name and age, and the participants were introduced the study and its aims. Group rules were made in that what was said in the group should not be told to others outside the group, they should not make fun of each-other's contributions to the conversation, and one should try not to interrupt when someone else was talking. This was followed by talking about European football teams as a "warming up" activity, and the participants discussed about their favorite team, but only small girls talked about it. This worked well in creating a relaxed atmosphere, where the participants talked and laughed, and seemed to be comfortable in the setting. The themes for these focus groups evolved around what makes a day a good day and the issues of disclosure of HIV status and stigmatization.

As mentioned previously, data collection consisted of interviews and observations of participants which allowed for the participants' voices to be heard, without a predetermined hypothesis of findings by the researcher (Richards, Foster and Sherr, 2006). Semi-structured interviews were developed and translated in to the local language

Amharic for social workers and children, to enable flexibility in the way questions were worded, to include probes if needed, and to allow for follow-up questions (Creswell, 2007). The interview questions evolved around what were positive resources in the children's lives, relationship with family and friends, their experiences of- and thoughts about- psychosocial, and how they handled stigmatization and other psychosocial experiences.

As shown in the appendix, questions began and ended with easy, 'light-hearted' subjects, to ensure the participants' comfort and to end off on a positive note. This lessened the risk of negative emotional or psychological feelings lingering from discussing such a sensitive subject (Cresswell, 2007). Observations and tap-recording were applied throughout the whole research processes. The observation approach gave insight into contextual issues like poverty, socialization customs and the interaction between family members, neighbors and peers of the interviewees. All the participants agreed that a tape recorder could be used during the individual interviews. This contributed to ensure that valuable information and quotes were not missed. Also, it was easier to interact with the interviewees and to listen actively when not being dependent on writing everything; furthermore it is sometimes not possible to write everything that is being said. To enrich the primary data, secondary data from the internet, books, brushers, different organizations' reports, strategic plans, training manuals and other relevant documents were also incorporated.

Location: to ensure the comfort of participants in an attempt to reduce power between researcher and participant and between children and adult (Green and Thorogood, 2009) all participants, except two children who are living with a sister and with a relative, were

interviewed in their home compounds where there were family members in far distance for privacy and also security. However, the two were interviewed in the social worker's home where they usually visit her for advice. Besides to this, the focus group discussions were carried out in the hospital center where these children usually visit for their medical treatments. It is likely that these locations further lessened the risk of child participants and caregivers carrying away negative feelings as a result of the interview and groups, as they were in their home and health center environments.

3.5. Data Analysis

After leaving the research site each day I transcribed and reviewed interviews and audio-recordings a number of times in a reflective manner to ensure the quantity and quality of data (Cresswell, 2007). Observations supported by check lists during interviews were also re-written with reflective notes to prepare for analysis. Transcripts and observations were then coded for emerging themes, followed by further reflection on how themes connect to psychosocial health, and the impact of the available sources on participants. It was determined that the content of the focus group data and the individual interview data did not differ markedly. Given the content similarities of the data collected, and the overall advantages of synthesizing mixed methods data to gain a richer understanding of a phenomenon of interest by eliciting a broader range and greater variety of perspectives from participants (Creswell, 2007), data from the focus groups and individual interviews were combined for the analysis.

The general approach to analysis was guided by a phenomenological framework as the study sought to understand the psychosocial experiences of children living with HIV.

The focus was on individual experiences and meanings given to those experiences, as well as shared experiences. In keeping with the ecological approach, attention was paid to the cultural and contextual themes within the data, with an eye to what extent psychosocial supports for young children infected by HIV/AIDS make them successfully coping and prepares them for future. When necessary**,** direct quotes of respondents were incorporated to give better explanation.

3.6. Ethical Considerations

Children living with HIV/AIDS and others who could have a contribution to this research were primarily asked for their permission to participate in the study. Initially, oral consent were obtained from children living with HIV/AIDS and their caregivers by the researcher in the hospital for those who join the focus groups. The social workers of the organization got for those who involve in the in-depth interview, then for those who were willing to participate in the in-depth interview informed consents were obtained from the legal guardians or parents. For the in-depth method of data collection, more than one contact was made with each participant. Once permission was granted from their legal guardians and interview settings were chosen, participants were informed about the objective of the research that might have affected their willingness to participate and answer the questions. Moreover, the participants were also cleared that they are free to choose to stay or break at any time of in the interview without giving consent; however, no-one was broken the interview. The participants were also informed that participation in this research was voluntary and that the participant might have withdrawn from the research at any time; that they have been granted no special

incentives for partaking in the research; and treat all the information obtained from the research participants as confidential. Their identities were concealed in written and verbal reports of the results.

The topics being dealt with in the study are sensitive themes that can be difficult to talk about and certainly sometimes could bring up bad memories and sad feelings. It was very important to let the participants know that they never had to talk about things they thought were too difficult to talk about or did not want to talk about and that they could stop at any time or withdraw from the study if they wish to, also during interviews. Also, if a topic should become too difficult for the participant, I could give the participant the option of another theme to focus on. No payment or gifts were given for participating in the study. However, refreshments were served before discussion in the focus groups at the hospital site, as it served as 'a breaking through' and as a compensation for spending time there.

Considering the benefits of the study to the participants, this study may not have any directly benefit to the participants, I also informed about this in the consent procedure. I hope that the results of the study will contribute to new knowledge about the phenomena, and may then benefit adolescents in the future, who are in the same situation as the participants in this study.

Chapter Four: Results

These results reflect the information gained from the focus groups, individual interviews with children and staffs, and observations made during the time spent with the participants. The report was prepared on the results related to the original research question, as mentioned previously. Each of the interviewed group's experiences was reported on, meaning from the view of the children living with HIV and the staffs working with them. The major themes that emerged in the study were presented and organized into two groups: positive resources and difference of living with HIV before and after disclosure. Organizing the themes avoids limiting the presentation of themes to only those that were endorsed by the majority of participants, since one of the major strengths of qualitative research is the representation of different voices (Creswell, 2007). Illustrative phrases and quotes from the focus group/individual interviews are presented below along with the gender of the individual.

4.1. Socio-demographic characteristics of respondents

Table 1: Overview of Participants

	Girls	Boys	Age	Grade
Individual Interviews	5	5	10-16	2-10
Focus Group	8	8	10-16	2-10
Staffs/key informants	2	1		

Out of the 26 children living with HIV and participants of this study, thirteen were boys and the remained thirteen were girls with 10-16 years of age. While four and six of

the respondents are living with their biological fathers and mothers respectively, eleven of them live with biological parents and the remained five live with aunts, uncle, sister, and other caregiver. Most of the children were infected from their biological parents, except for two, who were infected through use of a contaminated blade while their mother was shaving their hairs at the same date. The majority participants said that their fathers are working as guards and most of them also mentioned their mothers sources of income are petty trading, and a few said their mother has no sources of income. During this study all of the children are attending a regular school program ranges from 2nd to 10th grade in different places and receiving ART in the same treatment center.

4.1. Positive thriving resources

Children revealed the most important positive resources they experienced and discussed how they are succeeding in their lives with the HIV epidemic. Themes that emerged within the positive resources include knowing own HIV status, supportive relationships, leisure activities, and skills and meaningful activities. These psychosocial resources evolve around self-fulfillment, the treatment system and social relationships.

4.1.1. Knowing own HIV status

To be disclosed to own HIV status was very essential to the children. For the purpose of this study disclosure is being told about own HIV status, or to disclose own HIV status to significant others. All the children in this study had been told about their own HIV status and attending treatment in the hospital. However, they had been told at different ages, and some reported to have known their status for such a long time that they did not remember the disclosure process clearly anymore. The age when disclosure

had taken place ranged from around seven years old to twelve years old, with the majority being told after ten years of age. Physicians informed most of the children's status. Exceptions were two girls who had been told by their caregivers. The participant children found it important to be aware of their own status for several reasons, including knowing why they had to keep on taking medications and go to hospital's check-ups. One twelve years old boy explained the importance like this: "Because I was not going to understand why I am taking treatment". Other reasons that the children mentioned it as an important were to take care of themselves. A 16 years old boy expressed that "…we have to grow up knowing our status and how to live, to share our problems with others". Another, fourteen years old girl also pointed to how they had to learn to accept their status: "So that I can accept my status…, be comfortable and to accept everything that happens in my life". Furthermore, some of them also expressed a feeling of confidence because they after all knew their status, compared to others who did not know. A sixteen years old boy explained, "We have self-esteem because we know our status". The importance of disclosure was also evident in the participants' engagement when this theme was discussed. Most of them had strong opinions on it, and wanted to express why it was important to them. To a twelve years boy disclosure meant that he no longer had to go to check-ups at the hospital without knowing the reason for it.

Disclosure is also an important for the staffs of the hospital and the organization as well as for the social worker, and they thought the children themselves saw it as important to be disclosed to. The staff related this to enabling the children to know what was going on in their lives:

> "…they find it important for them to be disclosed to. So they really know what is happening in their life…they are starting to realize who they are, to take care of themselves…" (Organization staff)

The hospital staff emphasized that even though receiving an HIV diagnosis can be tough for the children and adolescents, making them feel sad, it gives them a chance to take care of themselves, the opportunity to live healthy:

> "…they can feel sad, but after all they know…they know how to look after themselves, take medicines properly, work with treatment staffs and handle themselves".

4.1.2. Supportive relationships

Children reported that receiving social support was a pivotal moment in their life. Within the general them of psychosocial supportive relations for children living with HIV and AIDS several subthemes emerged which include: a) treatment services, b) relatives, c) families, d) friends/peers, and religious programs.

Many children expressed that treatment services like doctors' advice, counseling and medical treatments were found to be important resources for them to live with the HIV epidemic. Medication was reported by the children to be one of the most important things for them. When asked about what made them feel safe or secure, all the participants replied one of the following statements: "the tablets", "only the tablets" or "taking on my treatment". Many of the adolescents also mentioned hospital staffs as positive resources.

"…health workers are very important for us. They just keep on supporting us, guiding, what to do and what not to do, even sometimes advice our caregivers in relation to our handling the problems".

However, hospital staffs were also revealed as a source of frustration among a few participants. Sometimes they felt that they were not treated well, especially when receiving their medications, the 16 years old boy explained it like this: "at the pharmacy there are some other people who make us sick...more than we are sick". They felt that the staffs in the pharmacy did not have enough time for them, and that they were not patient enough. They explained that since there were so many people attending treatments in the hospital and sometimes shortage of medicines were anticipated long waiting periods were common. All of them suggested that the hospital should allow a day in the weekend especially for children's and adolescents' treatment as well as reviews. They thought this would make the venue less crowded and shorten the waiting periods. Most of the time poor continuity when it came to the doctor visiting for their check-ups was also reported as a problem. The children thought it was difficult to develop a trusting relationship to the doctors when they often had to see different doctors at each check-up.

Children from all focus groups and individual interviews revealed that friends/peers in school and around community were very essential for their day-to-day life. Hanging out with friends was reported as one of the activities that made a day good, some also reported that being with friends was the most enjoyable part of the day.

"Things like your friends coming to your home to invite you to go and play. Then you stop feeling sorrowful. They make you happy; you play well without

fighting. To reduce pain, you follow your friends when they come. You go away from home."

"You might be sitting with them (friends), they start talking. You feel better."

The children reported family members as the first most important and major sources of support. For all participants the caregivers were the most important persons, especially mother and sisters, uncles or aunts and grandmothers were also mentioned as important sources of support. A twelve years boy mentioned how he felt loved by his family: "I just think it's the love they give me". In addition to giving love and support, family was also important in relation to giving guidance in life, sources of information, on what to do and not to do. Possibly one of the most significant relationships observed during in-depth interview is the relations between children and family members who know the HIV status of these children.

Extended family members were also mentioned as important for those who are living with their immediate family. For example, twelve-year-old girl told how she would go to her aunt to ask for food and get advice if her mother did not have enough to give her and get fight with her, and her aunt was also the one who disclosed the girl's HIV status to her.

"…in my case, when in pain, I cry and cry. And then I go to my aunt to get her 'counseling' and I should not cry since such things happen. She also encourages me to pray all the time. Not to think about the pain, but just pray."

"My uncle used to take me to his home and he would tell me what should I do and what should not. He would encourage me to go out and play with my friends and

to be happy. I used to listen to him and eventually I changed, I stopped thinking too much about it."

The staffs also mentioned the importance of the family's role. They were raising the importance of a supportive and encouraging family that were there for the children, communicating, making them feel supported. They also saw the importance of telling their children the truth, not to hide anything for them, such as their HIV status.

The staff thought that the waiting area in the hospital was often very crowded this is mainly happen since the center treats huge number of TB and HIV cases of Addis Ababa that this could be a stressful situation for a child who is left alone to go for his or her check-up.

"Even if there were ART centers in their closing areas, most HIV positive children and adults came to the center mainly I thought fear of stigma…" (Hospital staff)

4.1.3. Leisure Activities for psychosocial wellbeing

Participants discussed at great length leisure activities seemed to be important for the children with sports being the most important activity. The children were doing a range of different sports activities, but football was the activity most frequently mentioned for boys. Other leisure activities included playing with friends in and out of schools, watching TV, singing and dancing, going to the market areas, and two, one boy and one girl were very passionate about drama or acting.

Many of the youngest boys (10–16) said they played with friends when they were distressed or felt sad.

"…Usually after school and at weekends, I play with my friends. Besides, when the pain also comes back, I go to play football with my friends. It helps me a lot. After playing, I forget about what was bothering me…"

"…I used to go to my friends and play football or other games and sometimes we would just sit and chat. I used to feel much better after playing."

"I go out to play when the pain comes back. It helps me a bit but when I go to church to pray, all that pain disappears."

4.1.4. Skills and meaningful activities for psychosocial Wellbeing

Most of the participants reported that skills and meaningful activities such as school, reading, doing housework and cooking were as the main things they enjoyed doing. Furthermore, many of the participants had plans or dreams for the future that included further education. Because of this school was viewed as significant, but also as something they enjoyed. And what astonishing during the discussion and interview was that all of the participants also had specific things they would like to do or to be in the future to be a doctor and treat people "like us" to heal their problems and support them. Most of the children also wished to have their own sources of income so that they are able to support their parents.

To sum up, the children in this study had access to many positive resources, and most of the participants managed to effectively make use of these resources. Disclosure seemed to be an important factor for many of the participants, enabling them to take control over their own health as well as their social relationships. However, disclosure also seemed to be a key factor when it came to being able to access many of the resources

that were available to the children, including counseling services, information about HIV, treatment and how to live healthily and safely with HIV. Family was a very important source of support, as well as friends outside of the treatment system. Many had meaningful activities in their lives, both when it came to school and dreams for the future, and leisure activities.

4.2. Differences in psychosocial living with HIV before and after disclosure

Disclosure seemed to change the life situation of the participants positively and this was most evident when it came to knowledge about and understanding of their life situation.

4.2.1. Knowledge about HIV

Most of the participants discussed that disclosure enabled them to know how to take care of themselves and helped them to work with parents and hospital staffs for their treatment. Some said that if they did not know they would not have been caring about themselves in the right way. This was one of the reasons why the children saw it as important that they were disclosed to. Many of the participants stated how they were more able to take care of themselves after disclosure, such as:

> "Before I was sick, and weak, and usually cry… Even I refused my parents to go to school and to hospital…But, since now I know my status and when I grow up I can take care of my-self. If I did not know…I wouldn't be caring about myself" (a 14 years old girl)

After being disclosed to, the children were also able to access more knowledge and information regarding their status, and how to live safely with HIV. This particularly

occurred through different courses given in the school. Some also said that before disclosure they did not really know the meaning of HIV.

"I only heard that there was something like HIV…not really knowing the meaning of it" (A 12 years old boy)

The hospital staff also confirmed that information was one of the most important things they could provide the children with at the hospital. For some participants, when not knowing what the medications were for, and they had been told that it would make them feel better, it made sense to take the tablets whenever they felt ill. Problems with adherence also emerged as a result of not knowing their status; a 12 years old boy reported that he sometimes refused to take his medications, because he was angry about not knowing the reason for why he had to keep on taking the same medications.

"…it is important to know. Sometimes I just refused to take the pills" (a 13 years girl)

4.2.2. Understanding Life situations

Understanding one's life situation can be difficult when information about why things are happening is lacking. Many of the participants talked about having to continue taking medications without knowing why. A 12 years old girl explained that she could not understand this: "Why should I keep on taking the same medicine?" When asking for reasons for the never-ending medication regimes, the most common answer the children got was "to make you feel better".

"They said for me to get better. They just told me that if I don't take the pills I will continue getting ill" (a 14 years old girl)

For 12 years old boy, feeling angry and refusing to take his medications showed how the feeling of not knowing what was going on could contribute to make the life situation difficult and uncertain before he was told.

> "Because I was angry for them…why can I keep on taking these pills, then they just told me, mother always begs and father angry at me to take the medicines, but why?.."

The boy experienced to finally be disclosed to, when he started to question his medication regimen, and to refuse to take his tablets.

Furthermore, having to go to check-ups at the hospital could also be confusing before being disclosed to. A 14 years old girl experienced having to go to hospital check-ups without knowing the reason behind it. She expressed the importance of feeling strong and normal:

> “I will say the important things in my life right now, I’m strong, and I lead a normal life like each and every one other…”

She felt in control of her life, she knew how to lead her life, how to stay healthy and had access to social support, this might have enabled her to find peace in her situation. She also pointed out the importance of not giving up or losing hope when she was disclosed to. After disclosure she found it difficult to view herself as the same person she was before she got to know her status.

Both the hospital and organization staff confirmed many of the issues that the children reported above, talking about how it became difficult when the children were taking medications without knowing why, making adherence a problem, as well as confusing them, and potentially contributing to wrong use of the medications.

4.3. How to deal with Stigma

Stigmatization of PLHIV and AIDS remains a challenge in Addis Ababa, and was very much part of the reality for the children that participated in this study. Stigmatization is the main reason for people choosing to keep their status secret.

4.3.1. Protect themselves

To keep their HIV status a secret seemed to be one of the major coping strategies used by the participants to protect themselves from stigma. All of the participants reported that they kept their status secret from their friends and other people in the community. A 16 years old girl expressed that "I don't tell them because they will broadcast to other people, may also isolate me". The only one who knew about their status was their family; in some cases, family included the immediate family and extended family such as uncles and aunts. A 12 years boy explained why he kept his status a secret like this:

> "…it is because of they will just discriminate me, I think there will just come a time when they will discriminate me, and they will just shout at me like, in school, but when it comes when I grow up, nobody does that"

Many thought that some of the reasons for stigmatizing were lack of knowledge about HIV and its transmition methods.

> "…I feel like they will abandon me…I feel like they really don't know anything about HIV…" (16 years girl)

Most of the children used limitation of friendship both in school and out of school as a method to protect themselves. A 13 years old girl explained that

> "I have only one school girl friend for the previous four years, I don't want more…"

Furthermore, the staffs and social worker recommended children and adolescents to keep their status within their family until they grew older and were able to defend themselves from stigma.

> "I think they still have to keep it within the family…at that age they are still fragile minds…until the adolescent grows up, coming to a state where they can also defend themselves verbally… …if you start telling them that you are positive, most of people will run away…" (Hospital staff)

4.3.2. Confidence Development

Interestingly some of the participants showed a high level of confidence when discussing issues of stigmatization of PLHIV and AIDS. Some of them reported that knowing their status had developed strength to them, a girl stating that "I have self-esteem because I know my status" (14 years old). Thinking that maybe some of those who were stigmatizing might be HIV positive themselves, without knowing, helped them to ignore the person doing the stigmatizing. Furthermore, some of the participants said they knew it was not their fault they were HIV positive, they knew they had been born with it and that they were not to blame: "I have been born with the HIV-virus, not getting while doing other things" (13 years girl).

This knowledge and understanding that the people stigmatizing 'did not know what they were talking about' contributed to help them deal with it and to say it was better for them because they knew their status, than as for those who did not know. They explained

this by being able to take care of themselves and knowing what they were heading for, compared to those who did not know. The children in this study seemed to have found different ways of coping with the stigma they experienced, or the stigma they perceived would occur if they disclosed their status to the other people in the community. All of them chose not to disclose their status to people outside the family because of fear of stigmatization. However, many also found confidence in knowing their status, and managed to have a sense of pride in that they at least knew how to live their lives with HIV, compared to those who did not know their status.

To summarize the result, the lived psychosocial experiences of the children and working exposures of staffs interviewed for the purpose of this study were compiled. The analysis tried to show how children living with HIV thriving psychosocial challenges in relation with the HIV epidemic. Both medical treatment and the family were identified to be the most important sources of safety for the children. Participants seemed have developed strong confidence that they could live positively with their disease, and they felt strong because they knew their status and how to take care of themselves. Moreover, all of the participants saw it as important to be disclosed to, and most saw disclosure as important in order to be able to take care of them-selves and to understand their life situation. Furthermore, all the children never disclosed their HIV status to someone outside the family and important others because they feared that they would be stigmatized. Family and friends were important to most of them, and all of them had hopes and dreams for the future, but children seemed to gain only education material support from external sources like CBOs and/or NGOs.

Chapter Five: Discussions and Recommendation

In this chapter discussion was made based on the results presented in the previous chapter in light of previous literature and my own reflections. The discussion themes are divided into three sections: the positive psychosocial wellbeing resources, HIV related stigma copying mechanisms and life situations understanding of children living with HIV before and after disclosure of their own HIV status. However, many of the themes are closely related to each other, and it is sometimes difficult to solely focus on one theme without mentioning one of the others in the same relation. For this reason cross-reference was made as much as possible to show links between the themes. For instance disclosure is difficult to discuss without mentioning stigma and discrimination, but stigma and discrimination are also discussed in separate sections.

5.1. Discussions

5.1.1. HIV status disclosure as a positive resource

In this study it was found that being informed about own HIV status influenced the children's psychosocial life positively in different arenas of their life. This included being able to take care of themselves, to understand their life situation, to access social support, to deal with stigma, and in relation to psychosocial well-being.

All the participants in this study had been told about their HIV-positive status by their caregivers and healthcare workers. However, none of them disclosed their HIV status to their friends/peers in school or neighbors, except caregivers and staffs in the treatment center and organizations that provide treatment and some psychosocial

supports. This result reinforced the recent studies report on low levels of HIV disclosure to children and adolescents in SSA including Ethiopia as well as world-wide (Abebe and Teferra, 2012; Amare, Balcha and Solomon, 2013; Amzel et al.2013; Brown et al., 2011; Digsu et al. 2012; Valz et al., 2011). The low levels of disclosure seem to have remained in spite of evidence of positive effects of disclosing HIV status to children. Positive outcomes from disclosure of HIV status to children include good adherence to treatment regimen, better access to social support, and very importantly, children feel that it is important to know their status (Amare, Balcha and Solomon, 2013; Cluver et al, 2012; Deacon and Stephney, 2007; Digsu et al. 2012; Sherr, 2005). Some of the barriers for disclosing children's HIV status have been found to be the caregiver's fear of discrimination, social rejection and isolation for the child and the rest of the family if the child discloses to other people that the child is too young to understand, and that the caregivers feel they lack information about HIV to answer potential questions (Bikaako-Kajura et al. 2006; Deacon and Stephney, 2007; Hejoaka, 2009; Kanesathasan et al., 2011). These are barriers found worldwide, and can be seen as the caregiver's wish to protect the child.

Interestingly, a16 years old boy among the participants of the study was aware of the caregivers' dilemma of disclosing, and said that they also had to forgive their caregivers for not disclosing. He expressed that it wasn't their caregivers' intention to hurt the children by not disclosing it was a difficult situation for the caregiver. He thought that their caregivers maybe had a fear to tell them (section 4.2.1). The boy seemed to have a deep understanding of the dilemma their caregivers had when it came to disclosure of children's HIV status. His mother died from AIDS when he was about 11 years old,

and now he stayed with his aunt. He had been told about his HIV status when he was 13 years old, and he realized that the disclosure as a very important and even lifesaving event in his life (section 4.1.1).

However, it is still important to enable HIV positive children to create a way of living with the disease in a positive way, both when it comes to handling stigma, and the disease in itself, already from childhood age. This is difficult to achieve when the child is not informed about his or her status. When growing up with the knowledge, the child somehow gets used to the facts, compared to receiving shocking news at a higher age, when the child or adolescent might have defined the person he or she sees him or herself as. A 14 years old son, who said that after disclosure he had to do whatever it took to see himself as the boy he used to be before he was disclosed to (section 4.3.2), exemplified this. Daniel (2011) also poses an interesting view on this, arguing that the 'unknown secret' can actually be worse than knowing the reality (2011). Amzel et al (2013) suggest that when caregivers try to protect their children by not disclosing, adverse effects might be a consequence, for instance the child starting to fantasize and making up facts about the disease that might be hurtful. By not telling the child there will always be a risk that the child will find out from somewhere else, maybe without a supportive context (Sherr, 2005). Furthermore, there is also evidence that children sometimes know they have HIV, even though their caregivers have not disclosed to them, and are not aware that the children know (CRS, 2009). The participating staff in the study confirmed this dilemma, and explained how children who were not disclosed to often started wondering as they grew older, drawing connections between their own medications and the medications they saw on media (section 4.3.2).

Negative outcomes documented from disclosure are not as many as the positive, but in studies from the DRC and Puerto Rico, youth report initial emotional reactions such as getting upset or feeling sad immediately after disclosure (Sherr, 2005). Furthermore, there are reports of cases of crying, anger and symptoms of anxiety during the first week after disclosure; however, six months after disclosure negative emotions were uncommon in this group of youth (CRS, 2009; Sherr, 2005). This suggests that the negative reactions might be of short duration and that the adolescents manage to overcome the initial shock or negative feelings related to receiving the truth about their disease. In spite of these feelings, the majority of the participants still thought it was better to know what they were suffering from and felt that it was a benefit to them **(**Bikaako-Kajura et al., 2006; Blasini et al. 2008). The result of this study also confirmed that most of the children suggested initial negative effects of disclosure such as shocking and feeling sad and angry, but they could not trace the exact period it persisted. However, the focus of the study was to identify the positive factors, hence, the question of whether something was negative with disclosure was not asked directly.

Even though disclosure of children's HIV status continue to be a much debated issue, the majority of the people involved, including health care providers and HIV positive children and adolescents themselves, seem to agree that disclosure is important, positive and necessary in relation to many different aspects of children's lives. The next part of this discussion looked at the most important issues that emerged from the results of this study concerning disclosure of children HIV status.

5.1.2. Disclosure enabling children to take care of themselves

The participants in this study found that disclosure is very important in relation to many aspects of their lives, but the one most frequently mentioned was that disclosure enabled them to take care of themselves. They related this to the opportunity to learn how to live with their condition by gaining information and knowledge about HIV and the treatment regimen, enabling them to adhere to treatment, to use the medical and support services more actively, and to protect themselves and others from re-infection and infection of the virus.

All the participants in this study revealed that it was very important for them to be disclosed to, and they wanted to know their status. During discussion about disclosure, the children had given strong emphasis, and it was one of the themes that were discussed most actively by the participants. Studies from both Tanzania and the DRC (Amzel et al, 2013; Vaz L et al, 2008) report on similar findings, where children prefer to know their status. In Vaz's studies from the DRC, children express gratefulness that they were told about their status as children and not when they were adults (2008). In spite of negative feelings at the moment of disclosure they thought it was better to know what they were suffering from. Many of the children in this study expressed similar feelings, advising that caregivers should not delay the disclosure, and that it would have been worse to be told when they were adults. This view was also backed up by staff s from both the health center and organizations, where all of them got as important to be open with children about their status.

5.1.3. Disclosure to understanding life situation

For participants disclosure was also very essential for living with HIV and AIDS in order to be able to understand and accept their life situation. There are different patterns of disclosure, from not disclosing anything at all, to partial disclosure, to full disclosure.

According to Amzel et al (2013) partial disclosure is the most common form of disclosure, which means that the child is told something, but not everything about his/her condition. In addition, other studies suggest that a number of caregivers provide their children with deflecting information about their disease (Vaz et al, 2011). Giving the child deflecting information includes telling the child that he or she has a lung disease, allergy, or explicitly lying to the child by saying that he or she is sick, but does not have HIV (Daniel, 2011; Vaz et al, 2011). In this study, some of the participants seemed to have been partly disclosed to before being fully disclosed to. These children reported that before disclosure they were told that they had to take the medications to stay healthy and to prevent them from getting ill, or to make them feel better. And most of the participants expressed that they did not understand what was going on in their life in relation to having to take medications every day and go to hospital check-ups. When they were told that the medications were going to make them feel better, it was difficult to understand why they had to keep taking them when they did not feel ill.

The situation of not understanding what was going on clearly created a feeling of confusion. A 14 years old girl reported that she sometimes refused to take her medications because she was angry for not knowing why she had to take them. Similar reports are found from a study in Uganda, where children who were partly disclosed to had poor adherence and were questioning their medication regimen (Bikaako-Kajura et

al. 2006). Literatures from South Africa and DRC reveal that children frequently ask questions about their disease, and that caregivers still avoid disclosing to the child, giving other explanations than the truth or avoiding the question (SADC, 2011; Vaz et al, 2011). The participating health care staff in this study also reported similar situations. The staff from the hospital expressed about the existence of such situations (section 4.2.1). This situation was also very difficult for the health care staff that saw how disclosure would be beneficial for the girl, and how the girl was confused and curious about her situation.

For many of the participants in this study some aspects of their life were difficult to understand prior to disclosure, such as the medication regimens and hospital check-ups. Disclosure enabled the adolescents to make sense out of these life events, and also helped them to see them as meaningful and important. When it comes to the theory of sense of coherence with consistency and meaningfulness, it is quite clear that the situation changed to a more meaningful life situation after disclosure

5.1.4. Disclosure in relation to access social support

One of the most important reasons to support the disclosure of HIV status to children is that it improves access to or participation in social supports and treatment services. Key elements of psychosocial support for children affected by HIV and AIDS include: spiritual support, reduction of risks and vulnerability to HIV/AIDS, coping and resilience, life skills education, identity and goal setting, self-esteem and confidence, stigma management, learning through play, and peer care as youth prevention strategy. It was challenging in this study to clearly demarcate and describe the type and sources of social support; however, those social supports reported by the children participated in the

study are discussed below. The relationship between social support and disclosure has been discussed by Amzel et al (2013), who argue that "interventions to promote disclosure could facilitate access to emotional, encouragement, self-esteem and confidence development, material goods and information about medication and nutrition, reduction of risks and vulnerability to HIV/AIDS and peer support" (George et al. 2009).

None of the participants in this study have disclosed their HIV status to someone outside their family or the treatment and supporting organizations. This could be a coincidence, or it could be related to the fact that none of the participants mentioned any social support groups. This could underpin the important role support groups potentially can have in an HIV positive children's life. However, they reported to experience support from their family, both immediate and extended family. The participants (Section 4.1.2) saw family as the most important source of support. Several of the participants felt love and support from their caregiver and extended family. Two participants (12 years boy and girl) whose aunts also knew their HIV status reported to experience high level of support and encouragement from both their caregivers and the rest of their extended families. The girl explicitly expressed how she felt loved by her mother and grandmother which made her feel supported.

Disclosure of HIV status enabled most of the participants in this study to seek social support from support groups and organizations. Some of the participants reported that there were weekend group meetings that existed for a few months in the hospital. In these meetings children were joining with similar children and discuss openly about HIV and they revealed that the meetings were essential for them to engage with others who have similar life experiences, enhance the feeling of belonging, gain knowledge about

their conditions, and have a lot of fun together. Previous studies have found that being member of a social support group has a positive effect on adhering to medication regimens (Amzel et al, 2013). Furthermore, a review on the correlates between social support and adherence to medical treatment of a variety of diseases and conditions, found consistent evidence on the positive effects of social support on adherence (Obare, Birungi, Katahoire, Nkayivu, and Kibenge, 2009). However, disclosure by itself is not important without access to knowledge and social support through for instance group meeting, might not facilitate the same level of thriving as seen in this group of children. It seems the combination of disclosure and social support gave the children a unique group sense, a feeling of belonging, which seemed to be some of the key factors in their development of self-esteem and coping with HIV (also important in relation to adherence to treatment). It furthermore seems that this type of support also can enhance the process of disclosing own HIV status to others, outside the family, like disclosure to friends.

Studies suggest that supportive contexts, including supportive family and treatment systems enhance positive identities among HIV positive children, and children with an extensive supportive network appear to cope better with HIV (Amzel et al, 2013; Obare et al., 2009). This proposes that social support and extensive supportive networks can have a positive influence on HIV positive children' lives across different cultures and environments. However, since the participants' disclosure of HIV status is limited to close family members and treatment center staffs, the reported social supports were not far from such relationships and this has its own impact on the social development of children living with HIV and AIDS. This is supported by the work of Smith et al.(2008) who link the fear of stigma-related rejection to limited social networks and low self-

esteem and several studies note that keeping a secret increases stress and anxiety (Amzel et al., 2014; Smith, et al., 2008). Silence deprives HIV positive children of potential help since they cannot ask neighbors for support without disclosing the reason why (Amzel et al., 2013).

5.1.5. Disclosure in relation to handling HIV associated stigma

Interestingly, all of the children living with HIV found strength in knowing their own status, and reported that it gave them self-esteem. Previous research has also found that children who know their HIV status have higher self-esteem than those who do not know (Amzel et al, 2013). A recent study from Rwanda furthermore identifies self-esteem as a contributing factor in resilience in children affected by HIV (Vaz et al, 2011). Knowing their HIV status made the participants in this study able to take care of themselves (as discussed in section 5.1.1), but they also pointed out that there were people 'out there' who did not know their status, and because of this did not know how to take care of themselves. They also projected that those stigmatizing might be HIV positive themselves without knowing. As a strategy to resist stigma, the children felt sorry for those untested and in the dark of their HIV status. Disclosure in relation to being able to handle stigma is also closely connected to being able to use the treatment system more effectively and meaningfully when disclosed to (as discussed in section 5.1.1). The knowledge they obtained through the treatment system not only enabled them to take care of themselves physically, but it also helped them create a form of individual sense making, to know the reality, such as how the virus is transmitted, and get confirmation that being HIV positive was not their fault, but something they had been born with. However, because of the existing stigma such as fear of, most of children

have not disclosed their HIV status (Amzel et al, 2013; Deacon and Stephney, 2007), which means many miss out on the opportunity to effectively make use of the treatment system.

HIV – related stigma remains high in Ethiopia, and all of the children chose to keep their status a secret from people outside the family, as discussed in section 5.1.3. The children acknowledged some of the reasons for stigmatizing as lack of knowledge about HIV and how it transmits, and that people were stigmatizing without knowing what they were doing. These reflections again show how the children were able to make sense out of what was happening, because they had the appropriate knowledge to attempt to understand and explain the underlying causes of why people were behaving the way they did. The participants' conceptions about the reasons for stigma are confirmed in Sherr (2005) study finding that the level of knowledge about HIV and routes of transmission is closely related to the degree of social stigma. In spite of this knowledge, many of the children protected themselves by keeping their status a secret and thereby avoiding stigma. This can be an action of both protecting themselves, but also to protect their family.

Secrecy involves concealment, either by hiding something from the view or attention of others or by keeping silent about it and HIV related concealed includes status, ongoing treatment, receipt of medical and material aid and visits to the treatment center (Daniel, 2011). Direct stigmatization and discrimination against some HIV positive people, for example through labeling or exclusion, raises the fear of stigma among many others who have not necessarily had severe or direct experience of being

stigmatized. This fear of stigma then leads to HIV- affected people adopting coping strategies of secrecy and silence (Smith et al., 2008)

5.1.6. Disclosure in relation to psychosocial well-being

As discussed in the literature review (Section 2.3.1-3) the main factors for psychosocial wellbeing of children living with HIV includes pain and distress, chronic illness, and increasing disability as well as poverty and stigmatization. However, in order to address such issues disclosure of HIV status is very important for these children since it enhances social support (Sections 4.2.1 and 5.1.4). Studies strongly support this in that appropriate psychosocial supports for children could assist them to develop their emotional repertoire, their relationships with other people, their intellectual capacities, and their hope and motivation for the future (Richter, Foster and Sherr, 2006). These are best developed in nurturing and stable family environments with lifelong social connections, as these provide the necessary conditions for human development.

The result of this study indicated that the essential psychosocial supports that could enable children develop to their full human development are not reported mouth-fully; most of the participants are thriving and managing to remain positive, even though they knew that they are living with the virus and have to be on ART for the rest of their lives. Most of them have great hopes and dreams for the future and specific thoughts about what they wanted to do when they grew older. Most of the children were also involved in leisure activities that they enjoyed, and some were very passionate about these activities, finding it a very important part of their lives (section 4.1.5). The section above (section 5.1.5) shows how the children were more effectively able to deal with stigma because

they were disclosed to, and how they managed to create a form of individual sense making. In addition to this, the increased ability to access social support (section 5.1.3), improved understanding of life situation (section 5.1.2), as well as being more in control of their lives by knowing how to take care of themselves (section 5.1.1), contributed to an overall psychosocial well-beings among these children.

The participants in this study clearly showed how disclosure was a positive resource in their lives. They managed to take control over their lives by adhering to and actively participate in their own treatment regimens, they understood their life situation, were able to access social support and adapt coping mechanisms related to both the disease, and social issues such as dealing with stigmatization. Many of them were able to create a positive self-image, which in turn enhance their health and well-being in general.

5.2. The treatment system as a positive resource

5.2.1.Medical advice and counseling

Medical and nutrition advices and counseling during regular check-ups were also part of what the treatment system offered for the HIV positive children. Service providers in healthcare institutions are expected to provide social and psychological support to persons living with HIV (PLHIV) in order to help them cope with stress and to reduce the stigma directed against PLHIV (Garumma et al., 2012). The health care staffs working at the treatment facilities were also sources of support to the children, in addition to families, neighbors, and friends. A 13 years old girl expressed how the nurses and physicians at the hospital supported her, and guided her in what was right and wrong (section 4.1.2). This result confirms the study that states positive interactions with

healthcare providers can contribute to building coping mechanisms and resilience in HIV-infected children, whereas high satisfaction and trust in healthcare providers can reduce the negative effects of stigma on adherence (Amzel et al., 2013).

However, the regular check-ups could also be a challenging and sometimes a negative experience for some of the children due to, for instance often having to see different doctors. These challenges are more elaborated on in section 5.1.1

5.2.2. Antiretroviral treatment

Antiretroviral treatment has changed the course of the HIV and AIDS epidemic from being a fatal disease into being a chronic and manageable condition. Not surprisingly, ART proved to be very important to many of the participants in this study. The importance of ART to this group of children is closely related to the disclosure, as the participants would not have had the knowledge about the importance of their medications if they were not disclosed to. The children had a very strong confidence or trust in their medications, and the fact that they had access to ART seemed to be one of their most important sources of safety. When asked the question what made them feel safe or secure most of participants replied "the tablets" or "only the tablets" (section 4.1.2). ART is one of the main contributing factors to these children in managing to stay healthy and live long that naturally makes ART an important part of these children's lives. These findings are consistent with what Bikaako-Kajura et al (2006) found in a study from Uganda, where the children express similar attitudes to their medications, trusting the treatment will keep them healthy. In addition, a study from South Africa shows how life-prolonging medications can contribute to coping with HIV.

5.3. The Socio-ecological Theory and HIV affected children

Before the completion of the study, it is important to consider the Ecological Systems model of Bronfenbrenner (1979). This model was developed in a context where the complex interactions and relationships that individual and his /her multiple social and physical surroundings (environments) during child and adolescent development are seen as key to human development.

It is clear from the study that for these children, the children's microsystem consisted of their direct interactions with HIV or illness, family, significant others, peers, health-care providers, aid providers, and school. The mesosystem encompassed interactions between those in the microsystem including school and peers, income and parents, and significant others like extended families that may have caused aggravated their social or psychological problems among these children. Additionally, the macrosystem includes societal-level stigma and confidentiality laws that youth reported caused stress during that critical period following diagnosis.

According to Bronfenbrenner (1979), when the relation between different microsystems is compatible, children's development progresses smoothly (Hejoaka, 2008:3). Yet, if the positive outcomes of Bronfenbrenner's theory are considered the theory does seem to have some application. When reflecting the lives of the children living with HIV/AIDS in *Kolfe Keraniyo* sub-city, the limited children's HIV status disclosure with family and treatment centers majorly hampered the evidence that there are or are not smooth relationships among some micro systems such as schools, peers and neighbors. Even if having a positive relationship between staffs in the hospital, school, and organization and caregivers, staffs and children, and among children living with HIV

are vital for the development of these children as they are promisingly contribute to the children's psychosocial wellbeing. By creating positive relationships in their micro, meso, and exosystem and positively impacting the psychosocial wellbeing of the children, the results showed that due to limited disclosure of HIV status in children the relationships built among these were occasional, they were not smooth. The result showed that the major relationships that the children living with HIV established are selective and precautious.

5.4. Recommendations

The study undertaken in this thesis was limited in scope. It served as a lens to see the evidence that disclosure should be encouraged for all children and adolescence living with HIV. Furthermore, from this study it is evident that disclosure in the context of available treatment and social support facilitates advantages that disclosure alone might not be able to facilitate. This implies the importance of a well laid out medical and psychosocial treatment systems stretched from home to treatment centers which enables the children and adolescents to develop psychosocial wellbeing, in addition to the availability of social support.

Another recommendation is that group/club supports seems like a very appropriate setting for such children which facilitates a ground for them to speak with children about their feelings and their own interpretations about their play (Abadia-Barrero and LaRusso, 2006), and helpful in dealing with internalized stigma and being able to share with and learn from others who addressed the same difficult emotions/situations (Kanesathasan et al., 2011: 37). However, this has to be given strong emphasis.

Most of the reason why young children are not disclosed their HIV status is that most of their other family members are unaware of the diagnosis. Thus, while respecting the wishes of the parents in regards to disclosure, strong hospital staff-caregiver relationships could develop encouraging attitude from staff, as well as coaching and support, for caregivers to proudly disclose their family's status to family members and friends. In this way they may be empowered to become educators about their condition and continue to decrease the stigma surrounding HIV. This would reduce the chance of an educated child from disclosing new information, which may increase the willingness to educate young children, and possibly begin a generation of new attitudes towards the condition.

Considering further research, it would be interesting to do a similar study on a larger scale. Furthermore, the result also support to suggest comparing the psychosocial challenges of children living with HIV whose parents are publicly disclosed their HIV status with those who did not. Besides to this, even if data collection took place around home and it was made with children only, observations of the relationships between children and their caregivers and other family members were extremely minimal. Future research that includes observations of the child-caregiver, child-siblings, and child-teachers relationship may provide further insight into what makes psychosocial supports for these children successful. It would also be interesting to explore further the finding of children disclosing their own status to peers. Is this a phenomenon that is becoming more common in Addis Ababa, and what are the children’s experiences of disclosing their status to peers?

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Appendices

Appendix A: Interview Guide

Introduction

Good morning/good Afternoon. My name is **GashawAragie**. I am attending third year graduate school of social work at Addis Ababa University. This interview is part of the study and aims at exploring and understanding the psychosocial challenges that children living with HIV/AIDS are facing in their lives in Addis Ababa city. Your contribution in this interview could help in successfully accomplishing my study and future intervention pertaining to this concern. Your opinion and views in this interview will be used only for this study and will be confidential. Any personal identification like name and the like will not be included in the study. During the interview I will use tape recorder not to miss any points raised during the discussion. The tape recorder will also be confidential and will be used for analytical purpose only. Your honest and genuine answer to the issues will be great value for the study as well as addressing the problem of HIV/AIDS in our society. I would greatly appreciate your help in responding to this study. Your participation is voluntary, you may stop any time.

I. Focus group interview guide of child participants

1. What makes a day a good day?
2. Do you think it is important to let children/adolescents know about their HIV-diagnosis? Why?
3. What are your thoughts about stigmatization/discrimination of people with HIV?

4. What do you do if people treat you badly, i.e. call you bad things or exclude you from activities?
5. How does, or how can, family/friends/the community support you?
6. In what way can you help and support each-other?

II. Interview guide for in-depth interview of child participants

(To be used flexibly and adopted to type of informant)

1. Background data

1) How old are you?
2) What grade are you attending?
3) Who do you live with?
4) Do you have any brothers or sisters? (Do you all live together or are some of the siblings living elsewhere?)
5) Do your mother and father live together with you? Tell me about them?

2. Main Data

6) Can you tell me about what you do during a day?(morning duties, going to school, leisure activities, etc.)
7) Which parts of the day do you enjoy the most?
8) What things do you think you are good at? (for inst. school, helping out at home, playing football…)
9) Can you tell me about how you got to know that you have HIV? (who told you, when, where)
10) How did you feel? (Sad, scared…)

11) Do you feel that you can talk freely with your parents/caregiver about HIV, and that you get answers to your questions?
12) Do you think it is important that you were told about your status? Why?
13) Is there any family member that provides you special care and support to you? (encouragement, support in education,) What kinds of care and support?
14) Who does usually remind you about your timely taking of medicine? Is there any other related support?
15) Is there any person in the family who is not HIV positive? Can you tell me the relationship between this person and you (for disclosure and fear)?
16) Who knows about your disease apart from your caregiver? (Do you talk to people outside of where you get treatment about HIV/AIDS?)
17) What do you think are the challenges/what things are the most difficult in your situation (home, neighbors, community, school, health center etc)?
18) How do you handle them?
19) How do people that know you have HIV treat you?
20) Have you experienced to be discriminated against or in other ways been treated badly by other people? If yes, how do you react/what do you do?
21) What care and support do you get besides to medication in the center?
22) How often do you consult your counselor or doctor about your health?
23) How do you explain the treatments or approaches of the counselor or doctor in the health center?
24) Do you like going to the hospital/health center? Is there anything you don't like about it?

25) Do you have any school friends? Do they know about your HIV status?
26) Where did you put your medicine when you are in school and how did you use the time?
27) Did any of your classmates know about it? A school teacher?
28) How is important schooling to you? What motivates you to continue with schooling, and what you like and do not like about school?
29) What things are important to you? (families, relatives, friends, school, support, people in your community, availability of treatment, people in your religious community)
30) What sort of support would you most like to see young HIV-positive children receive from the adults in their lives? (From others?)
31) What are your goals and three wishes for the future?
32) Is there anything you would like to change to make you feel more happy?
33) Do you attend religious programs regularly? Why? With whom do you usually attend?

III. Practitioner/Worker Interview Questions

Introduction – statements stated in section I above will be used as an introductory opening.

Consent

I am going to ask you some questions related to psychosocial well-beings of children ages between 10 to 18 years living with HIV, which some people might find difficult to answer. Your responses are vital to make this study reliable and concrete. Your answers are completely confidential. Your name will not be written on this study. Your honest answers to these questions will help me better understand the psychosocial challenges of children in their day-to-day activities.

______________________ Agreed or ______________________ Not agreed

1) Can you tell me about your educational background?
2) For how many years did you work in the center and others?
3) Did you have any initial hesitations about working with children and families with/affected by HIV/AIDS? Do you still have any?
4) In what way do you feel that the center/hospital is a positive resource for the HIV positive adolescents visiting the clinic?
5) How would you describe the work you do?
6) Do you think that the children talk openly with the nurses, social workers, doctors and others if they need assistance or help with something, if they do what kind of questions or problems are most common among the HIV positive adolescents?

7) Can you tell me about the relationships between yourself and the child clients, and yourself and the caregivers?
8) Do you see a difference in the children you work with long term? Tell me about it
9) What are your hopes for the families who attend the center?
10) What does psychosocial (psychological and social) intervention mean to you?
11) What types of intervention do you provide for the children?
12) What do you think makes children and adolescents living with HIV feel safe and that someone is supporting them?
13) What do you think is most challenging for HIV positive children?
14) Is there anything you would like to add or share?

IV. **Caregiver's Consent for Child Participant**

I have been informed and understand the personal and professional risks involved for the child whom I should take care of by participating in this study. On behalf of the child, I agree to assume those risks, and his/her participation is purely voluntary, without any promise of special rewards as a result of his/her participation.

Signature______________________

Name_________________________ Date___________________________

V. **Table 2: Structure of codes / themes**

(The numbers in brackets after each code/basic theme represents the frequency of how many units/interviews in which the code was mentioned)

Table 2.1: Children

Codes/Basic themes	Organizing themes	Global themes
To know importance of medicines (25)	Disclosure	Positive factors
Family (26) Caregiver (26) Aunt (2) Church/mosque (gives guidance) (18)	Supportive relations	
Sports (13) Play (24) Being with friends (18)	Leisure activities	
School (26) Read (15)	Sills/meaningful activities	
Focus on life (20) Stay positive, don't give up (20) Accept status (25)	Accept situation	
Knowing why medications (25) Knowing why check-ups (24)	Understanding life-situation	Differences in living with the disease before and after disclosure
Knowing what HIV is (24) Know how to take care of themselves (25)	Knowledge	
Keep status a secret (26) Report if experience (23)	Protect themselves	How to deal with stigma
Poor family relationships (2)	Family	Challenges
Frequent family illness(10)		

To talk about HIV (5)	Communication	
Lack of transport cost for treatment (23)	Poverty	
Irregularity of ART provision(20)	Healthcare center	
Change of physicians(16)	Healthcare center	

Table 2.2: Staffs

Codes/Basic themes	Organizing themes	Global themes
Disclosure(30 Group activities(2) Open about status(3) Family aware of status(3)	Disclosure	Positive factors
Family Caring Open about status Baylor Group activities Medications		
Supportive relations		
Early disclosure(1) When start to read Tell straight away	Openness	Important in the disclosure process
Able to take care of themselves Adherence	Knowledge	Differences in living with the disease before and after disclosure
Know why medicines	Understanding life situation	
Keep status a secret Report if experiencing	Protect themselves	How to deal with stigma
Stigma Relationship to caregivers Relationship to peers	Feeling alone	Challenges

VI. The Amharic Version of interview guides

መግቢያ

እንደምን አደሩ/ዋሉ፡፡ ስሜ ጋሻው አራጌ ይባላል፡፡ በአዲስ አበባ ዩኒቨርሲቲ በሶሻል ወርክ ትምህርት ክፍል የሦስተኛ አመት ተማሪ ነኝ፡፡ ይህ መጠይቅ የትምህርቱ አካል ሲሆን 'እድሜያቸው ከ10 እስከ 18 ዓመት የሆኑ ኤች አይ ቪ በደማቸው የሚገኝ ልጆች በኮለፌ ቀራኒዮ ክፍለ ከተማ ማህበረሰብ የማህበራዊ እና ስነ-ልቦናዊ ተሞክሮ ለመቃኘት' የሚል ዓላማ አለው፡፡ የእርስዎ በቃለመጠይቁ እስከመጨረሻው መሳተፍ ለጥናቱ መሳካትም ሆነ በአርዕስቱ ዙሪያ ለሚደረጉ ቀጣይ ስራዎች ጉልህ አስተዋፅኦ ያለው ፡፡ ስምዎ ሆነ እርሰዎን የሚገልጽ ነገር በየትኛውም የጥናቱ አካል የማየጠቀስ ሲሆን የሰጡት ሀሳብ ወይም አስተያት ከዚህ ጥናት ውጪ እንደማይውል አስቀድሜ ላረጋግጥለዎት እወዳለሁ፡፡ ሐሳቦች እንዳያመልጡኝ እና ውይይታችንን የተሳካ ለማድረግ መቅረጸ-ድምጽ እጠቀማለሁ፡፡ በድጋሜ የተቀረጻው ሀሳብ የሚውለው ለዚህ ጥናት ብቻ መሆኑን መግለጽ እወዳለሁ፡፡ በርዕሱ ዙሪያ የሚሰጡኝ ትክክለኛ እና እውነተኛ ሀሳቦች ለጥናቱም ሆነ በአካባቢያችን በኤች አይ ቪ/ ኤድስ ዙሪያ ለሚደረገው አገልግሎት ትልቅ አስተዎጽኦ ያበረክታል፡፡ በቃለ-መጠይቁ በፍቃደኝነት በመሳተፍዎ ከልብ እያመሰገንኩ ያልተመቸዎት ነገር ካለ በማኝኛውም ሰዓት ማቋረጥ እንደሚችሉ አስቀድሜ መግለጽ እፈልጋለሁ፡፡

I. በቡድን ውይይት ለሚሳተፉ ልጆች የተዘጋጀ የውይይት መመሪያ

7. ለአንተ/ች አንድ ቀን ጥሩ የሚሆነው ምን ሲሆን ነው?
8. ልጆች/ወጣቶች ኤች አይ ቪ በደማቸው መኖሩን ቢነገራቸው ጠቃሚ ነው ትላለህ/ትያለሽ? ለምን?
9. ኤች አይ ቪ በደማቸው በሚኖር ሰዎች ላይ ስለሚደርሰው ማግለል እና መድሎ ምን ሐሳብ አለህ/ሽ?
10. ሰዎች ከተለያዩ ነገሮች ቢያገሉህ/ሽ፤ ቢያንቋሽሹህ/ሽ ወዘተ ምን ታደርጋለህ/ጊያለሽ?
11. ቤተሰብ፤ጓደኛ ወይም መሃበረሰብ በምን መልኩ ድጋፍ ያድርጉልሃል/ሻል?
12. በምን መልኩ ነው እርስ-በእረሳችሁ የምተረዳዱት/የምትደጋገፉት?

II. በግል ቃለ-መጠይቅ ለሚሳተፉ ልጆች የተዘጋጀ የውይይት መመሪያ

ሀ. መሠረታዊ መረ

ሃ. መሠረታዊ መረ

1. ስንት አመተህ/ሽ ነው --------
2. ስንተኛ ክፍል ነህ/ሽ -----------
3. ከማን ጋር ነው የምትኖረው/ሪው?
4. ወንድሞች ወይም እህቶች አሉሽ?ሁላችሁም አብራችሁ ነው የምትኖሩት ወይስ ሌላ ቦታ የሚኖሩ አሉ)
5. ከእናት እና አባትህ/ሽ ጋር ነው የምትኖረው/ሪው? እስኪ ስለነሱ አጫውተ/ችኝ

ለ. ዋና ጥያቄ

6. በቀን ውስጥ ምን ምን ስራዎችን ትስራለህ/ሪያለሽ?(የጠዋት ስራዎች፤ ወደ ት/ቤት መሄድ፤ መጫወት ወዘተ.)
7. በቀን የትኛው ጊዜ (ጠዋት፤ከሠዓት፤ማታ) ነው በጣም የምትደሰትበት/ችበት?
8. አንት.ች በጣም ጎበዝ ነኝ የምትልበት/ይበት ምንድነው? (ለምሳሌ በትምህርት፤ቤተሰብን በስራ በማገዝ፤ኳስ/ሙዚቃ መጫዎት)
9. ኤች አይ ቪ በደምህ/ሽ መኖሩን እንደት አወቅህ/ሽ? ማን ነገረህ/ሽ፤ መቼ፤የት?
10. ምት ተሠማህ/ሽ?(ብስጭት፤ፍርሀት፤ግራ መጋባት)
11. ከቤተሰቦችህ/ሽ ጋር በነጻነት ስለኤች አይ ቪ ውይይት ታደርጋለችሁ፤ለጥያቄዎችህ/ሽ መልስ ታገኛለህ/ሽ?
12. ኤች አይ ቪ በደምህ/ሽ መኖሩን ማወቅ ጠቅሞኛል ብለህ/ሽ ታስባለህ/ቢያለሽ?
13. ከቤተሰብ አባለት መካከል ለአንተ/ች የበለጠ ድጋፍና እንክብካቤ የሚያደርግልህ/ሽ ሰው አለ? ምን አይነት ድጋፍና?

14. መድሀኒትህን/ሽን እንዳትረሳ/ሽ እነድሁም ሌሎች ድገፎችን የሚያደርገልህ/ሽ የቤተሰብ አባል አለ?ሌላ ምን ምን ተመሳሳይ ድጋፍ?
15. ከቤተሰባችሁ መካከል ኤችአይቪ በደሙ ያለበት ሰው አለ? ያላችሁን የግንኙነት ሁኔታ ልትነግረ/ሪኝ ትችላለህ/ያለሽ?
16. ከቤተሰብ/አሳዳጊህ/ሽ ሌላ ስለአንት/ች ኤችአይቪ ሁኔታ የሚያውቅ ሰው አለ? ድጋፍ ወይም እንክብካቤ(ህክምና/እርዳታ) ከሚያደርጉልህ/ሽ ሰዎች ውጭ ስለ ኤችአይቪ ታወራለህ/ሽ?
17. ለአንተ/ች በአሁኑ ጊዜ እንደ ችግር የሚጠቀሱ ነገሮች ምን ምን ናቸው? በጣም አስቸጋሪ የሚባሉስ(በቤት፣ጎረቤት፣አካባቢ/ት/ቤት፣ ህክምና ቦታ ወዘተ ሊሆን ይችላል)
18. እንደት ተቋቁመህ/ሽ ታሳልፈዋለህ/ፊዋለሽ?
19. ስለአትተ/ኖ ኤችአይቪ ሁኔታ የሚያውቁ ሰዎች እንደት ነው የሚንከባከቡህ/ሽ?
20. የመገለል ወይም በሰዎች በመጥፎ ሁኔታ የመታየት አጋጣሚ ደርሶብህ/ሽ ያውቃል?
21. በሆስዘ ታሉ ጾመታኃቲፔ ሌላ ባምታ ገፁ/ዤው ተ ማሪ እንክብካቤና ድጋፍ አለ?
22. ከሀኪምህ/ሽ ጋር በየስንት ጊዜው ትገናኛለህ/ሽ?
23. ሀኪሙ/ሚ አንትን/ችን ለማከም የምታደርገውን አቀራረብና እንካብካቤ እንደት ትገልጠዋለህ/ሽ?
24. ውደ ሆስፒታሉ መምጣት ምን ያስደስትሀል/ሻል? ደስ የማይልህ/ሽ ነገር አለ?
25. የት/ቤት ጓደኞች አሉህ/ሽ? ስለኤችአአይቪ ሁኔታ ያውቃሉ?
26. መታኃቲቱት ፔምህርተ ቤፔ ስፔ ባ/ቢ ባፔ ኀው ባም ስቀምኀ ው/ ው? ስዓቱትስ እትተፔ ኀው ባምፔኀ ቀመው/ሚው?
27. ከክፍል ጓደኞችህ/ሽ መካከል ስለአንተ/ች ኤችአአይቪ ሁኔታ የሚያውቅ አል? መምህርስ?

28. መማርህ/ሽ ለአንተ/ች ጠቅሞሃል/ሻል?ማነው ትምህርትህን/ሽን እንድትከታተል/ይ የሚያበረታታህ/ሽ ማነው? በት/ት የምትወዳ/ጃቸው ወይም የምትጠላ/ያቸው ነገሮች አሉ?
29. በእስካሁን ጊዜ ለኔ ጠቃሚዎች ናቸው ብለህ/ሽ ደስ ብሎህ/ሽ የምታወራው/ዊው የትኛው ነው? በቤት፣ዘመድ፣ጓደኛ፣ ት/ት ቤት፣ ድጋፎች፣ የአካባቢ ሰዎች፣ህክምና ቦታ፣ የህይማኖት ቦታ?
30. ለሌሎች መሰል ኤችአይቪ ብደማቸው መኖሩን ላወቁ ልጆች ምን ትመክራቸዋለህ/ሪያቸዋለሽ?
31. የውደፊት ዓላማህ/ሽ ወይም ሦስት ምኞትህ/ሽ ምን ምን ናቸው?
32. አንተን/ችን በበለጠ ሊያስደስት የሚችል እና መለወጥ የምትፈልገ/ጊው ነገር አለ?
33. የህይማኖት ፕሮግራም በየጊዜው ትከታተላለህ/ሽ? ለምን? ከማን ጋር ነው ብዙ ጊዜ የምትሄደው/ጅው?