Addis Ababa University

School of Social Work

DISCLOSING HIV POSITIVE STATUS TO CHILDREN:

Challenges and Experiences of Parents and Guardians of HIV Positive Children

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Addis Ababa University School of Social Work

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Treatment
CBO	Community Based Organization
FHAPCO	Federal HIV/AIDS Prevention and Control Office
FMOH	Federal Ministry of Health
GO	Government Organization
HBM	Health Belief Model
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
IDI	In-Depth Interview
MTCT	Mother-to-Child Transmission
NGO	Non-Governmental Organization
PI	Personal Investigator
PLWHA	People Living with HIV /AIDS
PMTCT	Prevention of Mother-to-Child Transmission
TB	Tuberculosis
TRA	Theory of Reasoned Action
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nation Children's Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

Abstract

This study is a qualitative multiple case study that explored challenges and experiences in disclosing HIV positive status to children living with the virus. The study was conducted on fourteen parents and guardians who have regular follow up in Zewditu Memorial Hospital at pediatric ART unit. The data was gathered through in-depth interview. The interview guide was developed by adopting the already existing instruments and information prepared by ICAP (2003) frameworks on pediatric HIV disclosure, based on the objective and conceptual frame work of the study. The participants were identified through purposive and convenient sampling technique. To avoid unintentional disclosure of HIV status to the child or third person, interview was undertaken in isolated room. The data was analyzed thematically. The finding of the study shows that most of the children (9 out of 15) did not know their HIV positive status. The study raveled that challenges of parents and guardians from disclosing are low maturity level, and age of the child, fear of parents and guardians that the child will frustrate from living and learning, HIV related stigma and discrimination of the children as well as the family, and feeling of guiltiness in parents. Further more the study identifies various experience and patters of disclosure. Finally, the study has also drawn implications to social work knowledge, practices and proposed further research areas.

INTRODUCTION

Acquired Immunodeficiency Syndrome is (AIDS) pandemic is a disease that causes global crisis. It is unique in its rapid spread, extent and depth of impact in human history. More than twenty years after the first clinical evidence of Human Immunodeficiency Virus (HIV)/AIDS was reported, AIDS has become one of the most devastating disease humankind has ever faced. With no cure insight, the virus continues to spread and has become the third largest cause of death world wide (UNAIDS, 2004).

Adults AIDS, particularly the syndrome “slim disease”, was first described in the early 1980s. Pediatric HIV case was first observed in clinical services in the East Africa region particularly in Rwanda, in 1983-1984 (Tindyebwa D., Kayita J., Musoke P. , Eley B., Nduati R.,and Coovadia H.(2004). Since then it has evolved significantly on children (Minnefor, 1983).

UNAIDS’ and WHO’s report in 2007 showed that a total of 33.2 million people were living with HIV along the world. Among these, children younger than 15 years of age constituted 2.5 million, 90% of whom lived in sub-Saharan Africa. In 2007 alone, an estimated number of 370,000 children were newly infected mainly through Parent to Child Transmission (MTCT), of whom perhaps half were dying with out early intervention. Many of the 270,000 children who died in 2007 never received an HIV diagnosis or entered in to HIV care. The reports also show that an estimated number of 690,000 children needed Antiretroviral Treatment (ART). UNAIDS (2007) estimates that more than 1500 children per day are being infected with HIV globally. Most of the infection occurs through mother to child transmission (MTCT).

HIV /AIDS has a devastating effect with out discriminating people's socio economic status, religion, sex, ethnicity, age, and others through out the world (De Brynu, 1998). There are several potential modes of HIV transmission to children including MTCT (during pregnancy, labor, and delivery or, after birth, through breastfeeding), sexual transmission among adolescents, sexual abuse of children, transfusion of infected blood or blood products, un-sterilized injection procedures, and scarification (FHAPCO, 2007). The mode of transmission of HIV to children through MTCT is above 90% (WHO, 2007).

In developing countries, approximately one in every three children born to an HIV positive mother is themselves infected with HIV. In developed countries, less than one child in fifty born to an HIV positive mother is themselves infected. This is because of health practices including delivery, treatment with antiretroviral drugs and safe alternatives to breastfeeding. Children may also be infected with HIV through sex and unsafe health practices. Sexual spread of HIV is most common in older children/young people but can occur in younger children through sexual abuse. Unsafe health practices include use of non-sterile needles and unsafe blood products. These practices may also occur in the traditional health sector and include activities such as circumcision (UNAIDS, 2007).

Most children in developing countries who have HIV infection do not know that they are infected. There are many reasons for this. Many of these apply to adults also. HIV tests may not be available. People may not see the benefit of having a test, particularly if the child or adult does not feel ill (Tindyebwa,D., Kayita,J., Musoke ,P.,Eley,B.,Nduati,R.,and Coovadia, H., 2004).However, UNAIDS report that 'early awareness that a child has HIV infection, combined with good care and support, can enhance survival and quality of life of children.

Pediatric disclosure difficult for parents, guardians, and health care providers due to a number of reasons; HIV is a stigmatizing illness in most communities, parents and health care workers are uncomfortable talking about sex and HIV/AIDS to children, parents are afraid of how children will react, perception that children are much better off if they are shielded from "bad news", parents often feel guilty and feel it is their fault that the child is ill, parents and care givers often do not know what to say and cannot anticipate questions child might ask, lack of trained counselors to help with preparing families for disclosure and children may ask questions that he parent or caregiver cannot answer(Naeem-Sheik and Gray 2005)

Ethiopia is one of the hardest hit Sub Saharan African countries by HIV pandemic. According to the Federal HIV/AIDS Prevention and Control Office (FHAPCO), the prevalence rate of HIV/AIDS in 2007 was 2.1%. It is expected to rise to 2.2%, 2.3%, and 2.4% in 2008, 2009 and 2010, respectively, if no aggressive measure is taken. In 2007 it was estimated that there were a total of 977,394 People Living with HIV/AIDS (PLWHA), of which 64,813 were children in age ranging between 0-14 years and a total of 898,350 orphans. 258,264 PLWHA were in need of ART in 2007 of which 6.1% of them were children.

To this end, the main purpose of this study was to explore challenges and experience of parents and guardians in disclosing HIV positive status to their children living with the virus .The researcher focused on children living with the virus for the reason that disclosure of HIV status to infected children has received little attention and issues which are related to HIV disclosure in general and paediatric patients (children) in particular are becoming big problem world wide.

Statements of Problem

It is helpful for children to discuss their HIV positive status and the associated illness with trusted adults because it can improve their school attendance, performance, self-esteem, behavioral problems, stress, social functioning, depression, anxiety, and their adherence to treatment regimens (American Academy of Pediatrics, 2002).

Disclosure of the HIV diagnosis to children is a great challenge to parents, guardians, caregivers and the health professionals. Naeem-Sheik and Gray (2005) stated that disclosure process is much more difficult when the person being disclosed to is a child. One of the major difficulties is that dealing with many layers of disclosure including, the disclosure of HIV positive status of the child, the concomitant disclosure of HIV status of the parent/s and other siblings or other family members, and having to anticipate the child's own disclosure to his/her friends, extended family and community.

According to Sandra (1999) children who do not know their HIV/AIDS status are prone to develop fantasy about their illness, have difficulty in coping with their own illness or illnesses of other loved ones, have emotional problems and depression, feel isolated and are left to dark loneliness due to something unnamed but apparent. Consequently, the important parent child relationship will be affected and become full of mistrust. Struggling and frequent quarrels in dealing with medication will become usual.

When these children reach to their adolescence they might be involved in sexual risk behaviors and thus infect their partners or be re-infected by the virus (Tindyebwa,D., Kayita,J., Musoke ,P.,Eley,B.,Nduati,R.,and Coovadia, H., 2004). In support of this viewpoint, Naeem-Sheik and Gray (2005) and the American Academy of Pediatrics (1999) suggest that health care providers who deal with HIV infection in children need to develop a plan that will enable them to support parents in disclosure. During adolescence, disclosure of the diagnosis may also help to prevent high-risk behaviors, which could contribute to the prevention of HIV infection.

In Ethiopia, the socioeconomic condition, culture and way of communication style between families, especially between parents and children are not in a position to allow children to have any access of information about their illness and health status. Parents or guardians decide major issues for their children without involving them. Children are not given a chance to express their own views. (Kedija, 2006).

Disclosure of HIV positive status to infected children is not an easy task comparing with adults. This is because it is highly challenging as the same time pertinent issue for parents and guardians. Decision of disclosure depends up on the parents' and guardians' perception, attitude and knowledge toward the disease (American Academy of Pediatrics, 1999). Children are not the only one who decides to know about their own HIV status. But their level of maturity is low; they have their own psychological need and developmental milestone. Therefore, they need appropriate response and involvement in respect to their illness. The need to disclosure is imperative because their involvement in the medication regimen have a significant influence on their poor health condition. In order to become beneficiary of Anti Retroviral Treatment (ART) and other psychological treatments, they have to get the right and appropriate response from their parents and guardians (National Pediatric and Family HIV Resource Center [NPFARC], 1999).All these ideas prompted the researcher to ask the following questions:-

- ➢ What are the experiences of parents and guardians in disclosing HIV positive status of their children living with the virus?
- ➢ How do parents and guardians manage the illness of HIV infected children?
- ➢ What are the existing cues motivated parents and guardians to disclose the HIV status to children or not?

Objectives of the Study

General Objective

To explore challenges and experiences of parents and guardians in disclosing HIV positive status to their children living with the virus.

Specific objectives.

- ✓ To explore the experiences of parents and guardians in disclosing HIV positive status of children living with the virus,
- ✓ To assess the situations of parents and guardians in managing the illness of infected children, and
- ✓ To find out the existing cues which motivate parents and guardians to disclose or not.

Significance of the Study

Except research conducted by Kebede Derbe, Kifle Woldemichael, Mekitie Wondafrash, Amaha Haile and Alemayehu Amberbir (2008) and Hiwot Getachew (2006) which focus on disclosure to sexual partners and barrier to women public disclosure respectively, there is hardly any research conducted on the area of disclosure of HIV status to infected children in our country. Therefore, this study will contribute to knowledge building in this area.

It is also expected that the study may help health policy makers to develop strategies in addressing issue of HIV disclosure to children. The finding of the study will contribute a lot to social workers, HIV support groups (individuals of HIV/AIDS related health care providers), and various organizations that are working in favor of HIV infected children to advocate disclosure of positive status based on the children's cognitive ability, developmental stage, clinical status and social circumstance. The study will help, as a base line data, to those researchers who want to study further.

Conceptual Definitions

Disclose: To tell a child that he/she is HIV positive.

Guardian: Is a person who gives care and support for children who lost their parents due to HIV/AIDS.

Pediatrics: Is a branch of medicine which conserned about HIV/AIDS and the related health problem of children .

Counseling:the process of providing information ,education, and psychological support for HIV infected children and/ or their parents or guardians about HIV/AIDS in relation to children through professional relationship.

Asymptomatic:a personwho lives with HIV but not yet symptomatic.

Child: the person between the age of 6-15.

LITERATURE REVIEW

The word disclosure means to reveal, to make known, to make public, or to share once HIV status (ICAP, 2003).Disclosure is the act of informing others of a person's HIV status. Disclosure can occur in any contexts: with in personal relationship (to lovers, parents, spouses, children, friends and other family), in the workplace (to an employer, other employees, and clients), to health and other service providers (physicians, emergency services, social workers etc.), in an institution setting (prison, school, etc) and to the general public via the media (Canadian AIDS Society, 2004).

Disclosure of HIV Status to Children living with the Virus

Disclosure of HIV diagnosis to infected children is a challenging matter and complex process that presents challenge to families, guardians and health care providers. Stigmatization of HIV infection and concerns regarding children's ability to cope with knowledge of life-threatening often result in families working hard to keep diagnosis a secret. Families may fear being earmarked or ostracized. In other case, parents or guardians fear their children will "give up" and their health will decline once they learn their HIV diagnosis. Furthermore, because of the multidimensional nature of pediatric HIV disclosure to children often leads to difficult questions about transmission, parents' sexuality and/or drug use history, questions about their own death as well as their parent's. Secrecy becomes increasingly more difficult as children live longer, experience more medical treatment, interventions, hospitalizations, and grow into adolescents exploring sexuality in the "normal" course of development (Sandra, 2002; American Academy of pediatrics, 1999).

Approaches to disclosure of HIV diagnosis may vary between parents and health care providers, but one thing that has been established in many studies is that the child needs to be informed. Many suggests sooner rather than later during the course of the illness .It has been also suggested that, disclosure of diagnosis to child is an integral part of providing comprehensive medical care to the child infected by HIV and may influence positively on adherence to medication (Lipson, 1994).

Naeem-Sheik and Gray (2005) suggest that some families believe that disclosure to young patients will cause them harm, that the children could not understand death or the disease. Parent's feeling of guiltiness and the child's subsequent awareness to the parent's illness and potential death further complicate issue of disclosure especially in parentally transmitted cases i.e. when the child got HIV trough MTCT.

In general the issue of disclosure has long been debated among AIDS activists, the health care workers, and PLWHA. It has been stated that disclosure is a double-edged sword. On one hand, it may be constructive (the child may adhere to medical treatment); on the other hand it might be quite destructive (due to little age, and maturity level the child might be exposed to behavioral, and psychological problem) (Holt, 1998).

Patterns of Disclosure

As Chazal (2005) and Funck (1997) state, there are three types of disclosure: partial, full and non-disclosure. All are strongly influenced by the children's age, developmental level, as well as by parents' openness to speak out about HIV/AIDS. They are considered as a continuum and as part of the progression in providing information to children. As they describe, non-disclosure takes place particularly in the child's early years and it is totally no mentioning the name of the disease (HIV/AIDS) to the child.

Partial disclosure is describing situations in which children are given some but not all information about their illness .It is more commonly practiced in many parents and guardian. Children may be informed the need to take medicine in order to keep their illness at bay or learn how the virus can be transmitted without telling the illness's name (HIV/AIDS). Full disclosure takes place when children are told the name of the illness (HIV/AIDS), disease's specific information e.g. how the virus works, how it is transmitted, and how the children acquire the disease.

Discussion about HIV /AIDS with Children

Parents, particularly HIV positive parents, often feel shame or guiltiness for passing their own and the children's "illness," with all its social and medical problems, to their on children. As a result, consciously or unconsciously they avoid discussing about HIV with their children. Denial is common, relating to parents' own infection or the fact that their children are positive. Their feeling of discomfort to approach the topic comes from protecting the children from social stigma, and parental lack confidence in their children's social relation. They also worry that children will discuss their (the parents) as well as the children's HIV status openly, innocently, regardless of social context. As a result, they will expose themselves to countless outcomes of judgmental society (Schonfeld, 1997; Tindyebwa, D., Kayita,J., Musoke , P.,Eley, B.,Nduati, R., and Coovadia, H, 2004).

What, When and How to Tell?

Parents/caregivers are encouraged to begin and continue a dialogue about health issues with their children beginning at an early age by giving simple explanation about the nature and consequences of illness (Ledlie, 2001).The American Academy of

Pediatrics (1999) claims that disclosure geared to a child's level of cognitive development and psychosocial maturity. The exact diagnosis and prognosis of the disease are less important in discussions with little children. As children become mature, they should fully informed of the nature and consequences of their illness and should be encouraged to actively participating in their own medical care. Some parents and health care professionals are reluctant to informed children about their HIV infection status.

Disclosure is not an end by itself but a means through which the child lives better with his/her illness. It is integrated within the care offered to the individual (Garson, 2001). Naeem-Shiek and Gray (2005) affirm that disclosure is a process that should occur for long period, and should occur before the child discovers his or her own diagnosis. The American Academy of Pediatrics (2002) added that disclosure is not an event or a one-time conversation rather it is a process that takes time and constant communication with children in an age appropriate manner and based on their cognitive development level. It entails discussion on health and is health related activities, requiring systematic approach, various skills and is held in multidisciplinary team.

Disclosure should be associated with the child's developmental level of readiness to understand the complex and often challenging nature of HIV diagnosis and prognosis (Garson, 2001). According to the American Academy of Pediatrics (2002) and Lester (2002), disclosure can start at any age preferably as early as possible. Nevertheless, individualization depending on certain situations is required. What information to give and how to approach a child depends on the children's cognitive development, level of psychological maturity, and health status. Very young children might not understand the meaning of a diagnosis of their illness status and should not expect to comprehend the seriousness of their situation.

HIV Testing and Counseling for Children

Children and youth have unique venerability to HIV infection, as their ability to comprehend HIV/AIDS issues differ from that of adults. These populations demand special consideration .The welfare of the child could be the paramount guiding principle when considering testing; counselors have to determine reasons for testing with the parent or guardian (FHAPCO, 2007).

The Ethiopian guide line for HIV Testing and Counseling (HTC) states that, HTC for children under 15 years age shall only be done with the knowledge and consent of parents or guardians, and the testing must be done for the benefit of the child. However, children aged 13-15, who are married, pregnant, commercial sex workers, street children, and heads of families or sexually active are regarded as "*mature minors*" who can consent to HIV testing with out the knowledge of their parents or guardians (FHAPCO, 2007).

HTC is vital to ensure access to prevention, interventions and a critical gateway to treatment, care and support. Given the pandemic's current impact on infants and children, increasing their access to adequate diagnostic HIV testing and counseling services is essential and will help to ensure early identification of infants and children who are HIV-infected as a first step in securing their treatment and care ,identify infants exposed to HIV and children who are uninfected and may benefit from intensified follow-up, care and prevention measures that will help them to ensure that they are uninfected, and decrease potential stigma, discrimination and psychological distress for those children who are not HIV infected; increase the chances of adoption for orphans; and facilitate life-planning for parents and/or children who are HIV-infected. All these assist in the effective use of essential resources by targeting ART to those who need treatment (National Pediatric and Family HIV Resource Center [NPFARC], 1999).

A number of factors may prevent parents from testing their children for HIV. Health centers' may lack of technical ability, parents may be unwilling to take their child for an HIV test for fear that the child will face prejudice once diagnosed. Lack of knowledge about testing and the fact HIV can be effectively treated could also lead to poor testing rates. (FHAPCO, 2007).Parents that has not yet been tested may too be fearful of discovering that their child is infected, as this would likely mean they are infected also. Hospitals or clinics that provide testing may not be accessible and will lose contact with HIV exposed children for follow up tests. A parent may have to travel long distances to reach the nearest health service that can test her child, and this may be impractical and expensive (UNICEF, 2008).

Factors to Consider before Disclosure

Ledlie (2001) states, the following factors have to be considered both by the caretakers and health professionals before disclosing to children living with HIV. These includes CD4 count (Children who are more severely ill vs. asymptomatic), number of lifetime hospitalizations for the child, frequency of treatment and medication doses, psychosocial maturity, cognitive development, urban vs. rural setting(Children growing up in urban settings are often exposed to issues of sex and disease earlier than those in rural settings). ICAP (2003) added that before disclosure one should think about the needs, feelings, and beliefs of the child as well as the parent(s)/caretaker(s), current and evolving developmental and cognitive stage of the child, existing status of family dynamics, communication and multidisciplinary teams advocate for the needs of the family and the child.

Challenges and Benefits of Disclosure

As there are many challenges to disclosure, there are also benefits that have both short and long-term impact on behavior, parental and social relation of children; it helps to create a sense of closeness in family relationships, reduce feelings of anxiety and isolation (both for the child and family),helps to build social support networks, relieves the burden of living with the secret of being HIV positive, makes permanency planning more meaningful and increase the chances of success of the plan because the children can participate in the process, reduce anxiety that children experience because they suspect something is wrong. Children will have all the information they need to make better sense of the situation (American Academy of Pediatrician, 2002).

Although disclosure has a number of benefits, it is not without problems. Along with the aforementioned benefits, HIV status disclosure has many potential risks. According to Wiener, (1996) there are a number of challenges that HIV-infected individuals face when sharing their test results with friends, family and sexual partners. The difficulties that parents experience in making the decision to disclose is based on the real and imagined fears about how the family and the community will react. Some of the challenges are fear of stigma and discrimination associated with HIV infection, parents or guardians believe that if they disclosed the illness status to children, the child may not able to keep information confidential thus fearing the negative out comes of disclosure, psychological impact on children and on the other member of family including siblings and HIV infected child's emotional and physical health, and some cultures or families are not open about discussing personal subjects within family members especially with children. Due to reasons described here or others, an increasing number of children with HIV/AIDS are surviving to their teens or beyond without knowing their illness status.

If children could not get correct response in an age and development appropriate manner to their question in relation to their illness and not informed about their illness they might misinformed about HIV i.e. increases ignorance of HIV, poor health maintenance personal hygiene, less attending to visits doctor or hospitalizations, less participation in their own treatment, increased psychological and behavioral problems, decreased desire to access to support services, more complicated bereavement, difficulty to deal emotionally with illness, continuation of risky sexual behaviors, silence about their illness, isolation, stops asking questions, and tries to access information from other sources that may be inaccurate or unsafe (Ledlie, 2001).

Stigma and Discrimination

Stigma and discrimination may have significant short and long-term effects on behavior, social interaction and psychology of children both from their own experiences and that of their caretakers (USAID and UNICEF, 2008).

Stigma and discrimination against children infected and affected by HIV/AIDS prevents them from realizing the opportunities other children enjoy. These children can find it particularly hard to attend their education, and ignorance about HIV can lead them to being subjected to unreasonable fear and exclusion (UNICEF, 2006).

Children have been denied entry into schools because of their own HIV status or that of their parents. UNDP's (2007) report shows that in India, organizations providing care services for destitute children have carried out HIV testing for all children seeking services and have segregated or transferred those who test HIV positive.

Children infected by HIV and AIDS are experiencing high levels of stigma, including teasing, name calling, negative comments, abuse and neglect. Stigma was directed at children who are showing physical signs of illness or taking regular treatment (USAID and UNICEF, 2008).

Stigma towards children infected by HIV and AIDS can be social rejection or isolation (e.g. not letting a child with other children to play, making bad comments about a child, making the child eat or sleep in a different place alienating from other children), not giving children access to basic services and rights (e.g. not giving the child good treatment, neglecting a child in terms of food, clothing, education) (UNDP, 2007).

In Ethiopia, where burden of HIV-1 infection is greater (Max Essex, Mboup, Kanki & Kalengayi, 1994), the culture is so tight that the parent-child communication style is not open, stigma and discrimination is profound, majority of children are not expect to know their HIV status. Since, many peoples views HIV/AIDS as the likely result of promiscuity; thus, those who have the virus and eventually their orphaned children and the infected once are ostracized (Meheret, 2007).

Influence of Media on Awareness Creation about HIV/AIDS

The media can help raise awareness, counter myths and remove taboos about HIV/AIDS by making it an acceptable topic of discussion and providing accurate information about the disease and its prevention. Voices and participation of children can help break the silence and stop stigmatization (UNICEF, 2006).

Mass media with its wide reaching global infrastructure and communication expertise have a pivotal role to play in the fight against AIDS. More than 20 years to epidemic, public understanding of how HIV/AIDS is prevented and treated is mixed and basic awareness about the disease and its impact is solely lacking in many parts of the world (Agha, 2003). All over the world, if there had been similar initiative using media in raising awareness and offering people positive role model in the face of epidemic AIDS related stigma and discrimination would have been minimized (Norman, 2005).

American Academy of Pediatrics Recommendations (1999 p, 165)

1. Counseling for parents and guardians by a knowledgeable health care professional about disclosure to the child of their infection status.
2. Disclosure should be individualized to include the child's cognitive ability, developmental stage, clinical status, and social circumstances.
3. Younger children, if symptomatic with illness, discuss more immediate future. Do not need be informed of diagnosis, but the illness should be discussed.
4. The American Academy of Pediatrics strongly encourages disclosure of HIV infection status to school-age children. Symptomatic children, particularly those requiring hospitalization, should be informed of their HIV status.
5. Adolescents should know their HIV status. They should be fully informed to appreciate consequences for many aspects of their health, including sexual behavior.

6. Adolescents also should be informed of their HIV status to make appropriate decisions about treatment and participation in clinical treatment trials. Physicians should also encourage adolescents to involve their parents in their care.

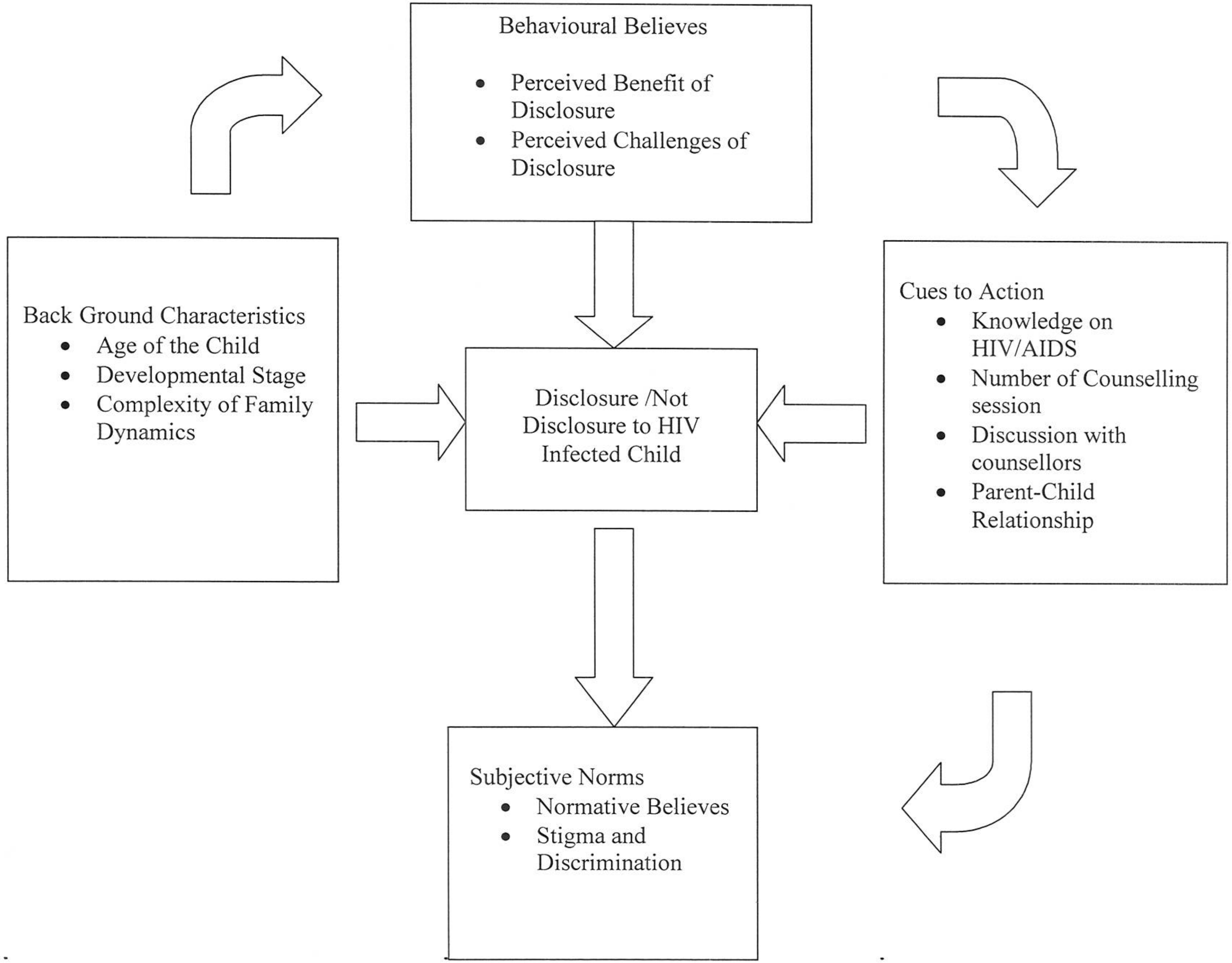
Theories of Behavioral Change

There are many models and theories of behavioral change. In this study, the researcher used the Theory of Reasoned Action (TRA) and Health Belief Model (HBM) as a conceptual framework.

HBM stipulates that a person's health related behavior depends on the person's perception of four critical areas: the severity of the potential illness, the person's susceptibility to that illness, the benefit of taking a preventive action and the barriers to taking that action. The model also incorporate cues to action as an important element in eliciting or maintaining patterns of behavior .The construct of self-efficacy or a person's confidence in his or her ability successfully perform an action has been added to the model(Champion, V.L. ,1984).

TRA states that individual performance of a given behavior is determined by a person's intention to perform that behavior. This intention is established by two major factors, the person's attitude toward the behavior (i.e. belief about the outcomes of the behavior and the value of this outcomes) and the influence of the person's social environment or subjective norm (i.e. belief about what other people think the person should do as well as the person's motivation to comply with the options of others) (Fishbein, M., and Ajzen, I., 2003).

The theory of planned behavior added to the TRA with the concept of perceived control over the opportunities, resources and skills necessary to perform a behavior. The concept of perceived behavioral control is similar to the concept of self-efficacy i.e. person's perception of his or her ability to perform a behavior .Perceived behavioral control over opportunities, resources and skills necessary to perform a behavior is believed to be a critical aspect of behavior change process (Fishbein, M., and Ajzen, I., 2003).


Behavioural Believes
Perceived Benefit of Disclosure
Perceived Challenges of Disclosure
Back Ground Characteristics
Age of the Child
Developmental Stage
Complexity of Family Dynamics
Disclosure /Not Disclosure to HIV Infected Child
Cues to Action
Knowledge on HIV/AIDS
Number of Counselling session
Discussion with counsellors
Parent-Child Relationship
Subjective Norms
Normative Believes
Stigma and Discrimination

By combining TRA and HBM, the researcher formulated conceptual framework. The researcher focused on the theory and model because both are used to enhance understanding of health related behavior of human beings in a better way. In this study the researcher tries to see the behavioral decision to disclose HIV positive status to children living with the virus by using the developed frame work.

While disclosing HIV status to children, background information of the child like age, developmental level, psychosocial maturity, and, the complexity of family dynamics should be taken into consideration. As the age of children infected with HIV has increased, the issue of when and how to disclose the diagnosis becomes a more critical issue that needs to be negotiated between health care providers and families (American Academy of Pediatrics 1999).

Parents' and guardians' decision to disclose or not disclose depends on the outcome of the perceived benefits and challenges of disclosure. If the perceived beliefs of disclosure exceeds to that of the challenges, Parents and guardians will disclose to the children. On the other hand, if the perceived challenge of disclosure exceeds than that of the benefit parents and guardians will not disclose to the children. There are also cues or driving forces like parent child relation, knowledge on HIV, Mass Medias, and discussion with counselors which initiate parents and guardians to disclose or not disclose (Lori S.Wiener, Haven B. Battles, and Nancy Heilman, 2000)

Stigma and discrimination are the major influencing factors that hinder parents and guardians from disclosing to the children living with HIV. Many well-intentioned reasons for withholding disclosure of diagnosis seem valid on face value like Protection of the child from stigma and discrimination, concern about child's mental health status and subsequent disclosure, to protect the child from social rejection, to protect the from fear or depression, parental sense of guilt or shame, and parental fears of rejection by the child (American Journal of Public Health, 2007).

Health professionals should anticipate the need for eventual disclosure when caring for HIV infected children. Although they can listen to and discuss with parents, mostly parents are reluctant to disclose. Thus, professionals should not accept parental or guardian requests to withhold the diagnosis under all circumstances. They need to inform parents that if children question them about their HIV positive status, they should respond truthfully. Although disclosure should occur in a supportive environment that optimally includes knowledgeable professionals and parents, some parents may decide to have professionals assume this responsibility. Ongoing counseling is required throughout the stages of the child's infection to obtain parental understanding of the importance of disclosure (American Academy of Pediatrics, 1999).

Due to the age, developmental level of children, and complexity of family dynamics behavioral believes (perceived benefit and challenge of disclosure to children) of parents and guardians to disclose or not to disclose to the child is determined. Behavioral believes predisposed by cues to action i.e. behavioral believes of parents and guardians are influenced by the parents and guardians knowledge on HIV/AIDS, their exposure to HIV counseling services, and parent child relation (American Journal of Public Health, 2007).

RESEARCH METHODOLOGY

Study Design

This research is a cross-sectional study which was conducted from April 1-May1 2009. The study was designed to explore challenges and experiences of parents and guardians in disclosing HIV positive status to their children living with the virus. The study is qualitative under the category of multiple case studies. Since HIV status disclosure to children is a new issue which has never been addressed with a certain sample or group of people in our country, qualitative study is the appropriate approach to explore the issue. The approach is also important to recognize human behavior. It gives new, in-depth understanding, and insight about the problem. Hence, qualitative study is an appropriate approach to address such kind of sensitive issues.

Study Area

At the beginning, the researcher aimed to conduct the research in Black Lion Hospital, which is general, central, specialized, referral, and teaching hospital found at Addis Ababa University. However, due to the long process (two to three months) to get an ethical clearance from the hospital, particularly from the Pediatric ART Unit, the researcher changed the study site to Zewditu Memorial Hospital, which also gives similar services for clients. The interview with the counselor Nurses show that both hospitals are pioneers to start ART in 2003/4 for pediatric patients in our country.

Zewditu Memorial Hospital (the name after Queen Zewditu- the queen of Ethiopia crowned in 1920s) is found at the heart of Addis Ababa and recorded a history of more than 45 years of service in the health sector. The hospital gives general health service for those clients who come from all corners of the country. The repot of the Hospital (2007) shows that Pediatrics ART unit is one of the clinics found in the hospital and gives various services for pediatric HIV patients. Among the services, Voluntary Counseling and Testing (VCT) services for clients between the age range of 13 -17, HIV related health education, follow up and clinical check up, assessment of growth and development, identification of eligible patients for ART and implementation of this treatment to HIV infected children under 17.

Study Participants

The monthly report of the Hospital shows that at the end of April 2009, there were new and cumulative numbers of 23,949 HIV Positive children which include less than 18 months to 17 years old. Out of which, 15, 003 of them were enrolled on pre-ART and the rest 8,946 children were enrolled on ART.

The clinic gives service for children with HIV infection from Addis and other parts of the country. To this end, pediatric ART clinic of Zewditu Memorial Hospital was selected for this study. As it is mentioned earlier, pediatrics related HIV treatment was held for the first time in Ethiopia at this hospital (for pilot study). In addition to this the area is ideal for pediatric HIV/AIDS related activities.

This study was conducted on parents and guardians of HIV positive children with the inclusion criterion of:

1. The participants should have to know the children's HIV positive status at least a year before. This will help the researcher to become sure that participants have adequate experience and challenging situation to share.
2. The participants should have children that are HIV positive and fulfill the operational definition of children in this study (6-15 years old). This was done by taking an assumption that mostly children under the age of 6 may not

comprehend things well and not understand the concept of death and disease. Children above 15 years old are also considered as matured enough to get informed consent for themselves. (FHAPCO 2007).

3. Priority was given for participants who are willing to share their experiences and challenges with self-exploratory ability on the issue under study.
4. In order to gain perspective and reflections on challenges and experiences of disclosure, counselor nurses with the inclusion criteria of those who are working in the unit with special training on HIV counseling services were approached. This was done by taking an assumption that these counselors have a close relation with the parents and guardians on discussing on the issue of disclosure to children.

Sampling Technique

As this study was conducted through qualitative research method, the participants were selected by using purposive and convenient sampling techniques. Since the data was collected within a specified period of time, participants were selected purposefully based on the outlined inclusion criterion. As Berg .B.L. (2001) expressed, in purposive sampling technique, the participants are selected based on the objective of the study, and by their experience on the issue. As the name indicate, in convenient sampling participants are selected based on their accessibility on the specified time and place.

Methods of Data Collection

During the process of research, the qualitative investigator may collect documents which include public documents, papers, etc. (Creswell, 2003).In this study, both primary and secondary data was utilized as sources of information. Secondary data was gathered from books, broachers, and articles. The secondary sources were embodied in the discussion part to enrich the study.

By using qualitative data collecting techniques, particularly In-Depth Interview (IDI), the primary data were collected. The rational to select this instrument was to generate data in detailed form. It is also effective to draw out in-depth information from the participants in relation to their experience, feeling, thought and understanding.

The Interview guide was developed by adopting the already existing instruments and information prepared by ICAP (2003) frameworks on pediatric HIV disclosure, in addition to the objective of the study and conceptual frame work.

The instruments were first developed in English and translated to the local language (Amharic) by the Principal Investigator (PI). The similarity and clarity of ideas between the translated and the original guide was checked by a language teacher who is fluent in both languages.

Interview involves un-structured and generally open-ended questions that are few in number and intended to elicit views and opinions from the participants (Creswell, 2003). The Interview guide was prepared in the form of open ended and unstructured questions encompassing all demographic and social characteristics of the parents and/or women guardians as well as that of the child: - age, sex, religion, educational status (parent and guardian and the child), marital status, occupation of (parents and/ or women guardians) and the relationship to the child.

The main thematic areas covered during interview with parents and guardians included how participants' learned the positive status of their children, their feeling at the very moment they heard the result, the awareness of the children about their HIV status, disclosure experience of the participants, parent-child relation and intimacy before and after disclosure, feeling of children in taking medication, emotions related to hospital visitations and the cue factors which motivated them to disclose or not.

To ensure the easily understandable nature of instruments and make corrections of misleading and unclear questions, if any, pre-test was done prior to the actual data collection time at the same settings (Zewditu Memorial Hospital) on two clients of the ART Unit. These two clients were excluded from the actual study since they are interviewed to check the clarity of the developed interview guide. Finally the necessary correction was taken.

The fourteen participants were obtained while they came to the hospital to collect drugs for their children within the specified time table (April 1-May1, 2009), before conducting the actual interview with each participant, individual meeting was arranged for getting informed consent and to build a good rapport. Qualitative researcher looks for the involvement of their participants in data collection and seeks to build rapport and credibility with the individuals in the study (Creswell, 2003). At the initial meeting, self introduction and clarification of the objectives of the study was done and the actual interview also proceeded for most of the participants. Since getting parents and guardians who had disclosed to their children was very tedious, the last utilized resort was phone call by the help of the counselor nurses. For these participants, after clarifying the objective of the study, date and time to meet with them was arranged. Interview for the entire participants' was tape recorded. Note taking was undertaken to document the data when interview was made with each participant.

Among the approached eighteen parents and guardians, four (three males and one female) of them were not willing to participate in the study due to their own personal reasons. As a result the incomplete data was discarded.

Method of Data Analysis

Since the process of data analysis involves making sense out of text and image data, it requires the researcher using different analysis techniques, moving deeper and deeper into understanding the data, representing the data and making an interpretation of larger meaning of the data (Creswell, 2003). After the collection of the data, it was transcribed in the local language (Amharic) and translated in English for analysis. In the over all process of transcription and translation, maximum effort was exerted not to distort the original meaning of the information by cross checking the accuracy of the recorded document and the translated data. According to Creswell (2003) organizing and preparing of data for analysis involves transcribing interview, sorting and arranging the data in to different types depending on the source of information, reading through all the data to obtain a general sense of information and to reflect on it's over all.

Transcription and translation was followed by the coding system and thematic development process. Again the process of coding was followed by development of categories and themes. As Crotty M. (1998) explained, the process of coding help to generate small number of themes or categories, which appears as major findings in qualitative study and are stated under separate heading in the finding section of the study. Categorization process was finished by putting each coded segment in detached files. Then the identified categories were assorted into thematic issues. Finally, the cases were analyzed thematically.

Ethical Consideration

The highest ethical standard was maintained during the data collection process since the issue of HIV disclosure to children was stigmatizing, as well as, it is human rights and confidentiality issue.

Study participant may experience harm during the process of data collection or after dissemination of the study result. On the basis of this justification, the primary task of the researcher was to get approval of the proposed research from the School of Social Work, Addis Ababa University. The school approved the research proposal and allowed continuing the research after giving a written consent to Zewditu Memorial Hospital. Permission was obtained from Zewditu Hospital Medical Director and Pediatrics Clinic ART unit head. The researcher met with the staff in the hospital pediatric ART unit so as to build good rapport and to explain the nature of the study, it's over all process, the time required to collect the data. Finally, they agreed to prepare room to avoid accidental disclosure both for the infected children and the third body while the data collection process was going on.

Since the topic under discussion was quite sensitive, it was mandatory to have participants who are volunteers in sharing their personal experience and secrets. Thus, it helped to minimize the negative effect on the participants as a result of participating in this research.

The researcher had also discussed with each participant to get their consent. Before the beginning of the actual data collection, the participants were informed that they had the right to withdrew from the study any time and this would not affect the treatment that they are receiving in any way. Finally, in order to keep the confidentiality of the participants, their names were not exhibited on the report. To avoid unintentional disclosure of HIV status to the child or third person, interview was undertaken in isolated room.

Limitation of the Study

Since the nature of the study was purely qualitative and the main method of data collection was IDI with fourteen parents and guardians, it was obvious that the finding of the study is not going to be generalized to all children living with HIV who are receiving service in the Paediatric ART unit.

Getting any kinds of data and rate of disclosure to children living with the virus at the study site as well as in our country context was the major limitation of this study. Finally, since three male participants withdrew from the interview due to their own personal reasons the participants of the study became only females; this was also another major limitation of this study which hindered the researcher from getting information, and perspectives from male parents and guardians.

FINDING OF THE STUDY

Socio-Demographic Characteristics of Respondents

Table -1 Socio-Demographic Characteristics of the Respondents. Zewditu Memorial Hospital, April, 2009 (N=14)

No.	Respondents	Age	Educational Status	Occupation	Religion	Marital Status	Relationship with the child
1	Participant	30	Elementary completed	NGO Employ	Orthodox	Single	Mother
2	Participant	49	Illiterate	Daily Labourer	Orthodox	Widowed	Mother
3	Participant	22	High School Completed	Student	Orthodox	Single	Guardian
4	Participant	60	Illiterate	House Wife	Orthodox	Widowed	Guardian
5	Participant	35	High School Completed	House Wife	Orthodox	Married	Mother
6	Participant	38	High School Completed	Government Employ	Orthodox	Divorced	Mother
7	Participant	52	Illiterate	House Wife	Orthodox	Widowed	Mother
8	Participant	30	Elementary Completed	House Wife	Protestant	Married	Mother
9	Participant	32	Collage Diploma	NGO Employ	Protestant	Married	Guardian
10	Participant	35	Elementary Completed	House Wife	Orthodox	Married	Guardian
11	Participant	41	Literate	Daily Labourer	Orthodox	Widowed	Mother
12	Participant	29	High School Completed	Private Business	Orthodox	Widowed	Mother
13	Participant	46	Collage Degree	NGO Employ	Orthodox	Married	Mother
14	Participant	48	Elementary Completed	Government Employ	Orthodox	Married	Guardian

As shown on table 1, from the total of fourteen participants, seven were between 25-35 years-old, followed by three between 47-57 years old. Four participants completed elementary school another four were high school completed, three were illiterate (cannot read and write), one can read and write (but not attended formal school), one participant has college diploma and another participant has college degree. Five participants were housewife, another three were NGO employees and two were government organization employees.

In terms of their religion, twelve participants were Orthodox religion followers and the other two participants were Protestants religion followers. Regarding the marital status, six participants are married another five were widowed, two were single and one was divorced. Lastly, nine participants were parents of HIV positive children, the rest are guardians.

Table-2 Characteristics of Children Living with HIV Zewditu Memorial Hospital, April, 2009 (N=15)

No.	Sex	Age	Educational Status
1	F	14	Grade 8
2	M	6	Kindergarten (KG)
3	M	7	Grade 2
4	M	9	Grade 2
5	F	14	Grade 4
6	F	13	Grade 6
7	F	9	Grade 2
8	F	12	Grade 6
9	M	15	Grade 9
10	M	8	Kindergarten (KG)
11	M	11	Grade 5
12	F	6	Kindergarten (KG)
13	F	10	Grade 3
14	M	8	Kindergarten (KG)
15	F	13	Grade 5

As shown on table 2, from the total of fifteen children living with HIV the number of female and male children was almost equal, eight girls and seven boys. Five of them were between 8-9 years-old, and similarly another four were between 13-14 years-old. Three children were grade two students, two were grade five students, another two students were grade six students and four were kindergarten students.

In this part of the paper, the major findings of the study are presented in a thematic approach.

Experiences in Disclosure

The first specific objective of the study was to explore the experience of parents and guardians in disclosing HIV positive status to their children living with the virus.

Experiences of Knowing Children's HIV Positive Status and Feeling at that Moment

At the beginning all participants were asked about their experiences in their curative action measure when they fall sick (health seeking behavior). All of the participants responded that they had taken a remedial action for their illness through visiting modern health service centers. Exceptionally, one of the interviewees responded that her primary recourse was praying. If her praying hasn't brought change she would visit modern health service providers. None of them have chosen traditional healers.

But the interview with key informants shows that counselors criticize and blame those who use holy water for HIV treatment. Sometimes they impose on parents and guardians to choose only one treatment system, either the religious or scientific one particularly for those who did not adhere to ART and inclined more on using holy water.

The participants were also asked about their knowledge on HIV/AIDS. Their response indicated that even though their level of awareness varies from one to another, they have basic knowledge about HIV/AIDS like the mode of transmission and prevention.

The In-depth Interview (IDI) result indicates that almost all of the participants learnt the HIV positive status of their kids as a result of continuous illness of the children.

From the response of participants, the researcher identified three different experiences of knowing the sero-positive status of the children. The first experience comprised of parents who were able to became familiar with the sero-positive status of their child before knowing their own HIV test results (either positive or negative). These parents explain that after frequent illness of their children they took the kids to hospital. One of the parents was initiated by the health professionals to get HIV blood test for her child. The other one was motivated by herself to test her child for HIV because almost all of the examination results in different Hospital showed different diagnosis. However, the latter parent faced challenge from the health professionals to test her son for HIV. Finally they ordered her to bring the child's birth certificate to check her relation with the child, since at that time getting HIV test for children was rare. But after getting HIV blood test both of them learnt the sero-positive status of their children. At the moment these parents did not test their blood for HIV.

The second experience is learning the sero-positive status of the children after their own (parents) examinations. All of them took their children to hospital after looking the poor health condition of their kids. Exceptionally, one parent decided to test her daughter without looking any symptoms. Above all, she seeks advice from pediatrician in order to know two things. The first was if her daughter is free from the virus, how to protect her from being infected and if she is already infected how she (the parent) could give care and treatment for her daughter.

Most participants reported that they developed a feeling of suspiciousness about their children's positive status before testing the children for HIV and began to blame them selves about the over all situation. Some of them would say "O *my child, you are suffering from the sin for which I had committed*".

There was a parent who had learnt her child's sero- positive status after the child had already started ART but she knew her HIV positive status earlier. She explains the situation spontaneously as:

> *I have an 8 years old son. I heard his HIV positive status after he had started ART. This was because when the child was sick, I was also critically sick due to the existence of the virus in my blood. My sister had taken him to the hospital and he was admitted there for two months. Since my husband had died, the health professionals did not tell his status to my sister. But I was able to understand the child's status when I went to the hospital to collect his drugs. The counselor nurses were talking about ART, I immediately asked them the type of drug which my child is taking now. She was confused and asked my relation to the child. After knowing that I am his parent, she gave me a counseling service, and informed me his HIV status. At that moment, every thing was seemed up side down. I fainted out. Until that instant, I assumed he was taking Tuberculoses (TB) tablets.*

The last experience of knowing the HIV positive status of children was practiced by women guardians (who had adopted the children after the death of the children's biological parents), as a result of poor health condition of the children. Thus experience of parents and guardians who were learnt HIV positive status of their children was diverse.

The succeeding question forwarded for the participants was their reactions and feelings at the very moment when they came to know their child was infected by the virus. The participants explained their reaction and feeling in various ways. Some of them were distressed since they did not expect the result. Others wept bitterly, with deep sorrow becoming anxious about the subsequent stigma and discrimination, and had attempted suicide. Paradoxically, there was one parent who took the result easy merely by considering as a relief identifying the type of disease her child is suffering from regardless of the type of the disease.

Another participant explained that even if she decided to test her daughter for HIV by self initiation, she was unable to wait for until she knew the result since the issue is very challenging. She became the first person to enter in to counseling room together with the doctor. When the doctor started to explain about what has to be done for the child in the future, she just asked him to tell the results only first. After knowing the diagnosis, her tear started to flow without interruption. It was after having long counselling services hours that she stabilized her self, started to think and discuss about the future intervention plan.

The response of the women guardians was more or less similar except the feeling of blaming oneself. But they felt deep sorrow, feared a lot, kept on weeping and praying. There was one guardian who felt nothing when she understood the positive status of the child which she took care for.

Another guardian explains her feeling at that moment as follows:

> *When I adopt both of them (a boy who was 11yeas old and a girl who was 6 years old), the first thing I did was test their blood for HIV. Unfortunately, the results were awful .I was very much confused and disturbed. I felt very bad because these children are too much innocent, but are suffering from others' sin and mistake. These made me very much angry and feel sorrow. On the other hand, I was with full of hope, strong belief and happiness because I believe that God will cure them one day.*

The response obtained from the nurses also shows the experiences in learning the sero-positive status of children and the reaction which the parents and guardians show is similar with that of the response obtained from parents and/ or women guardians. They added that mostly females are the ones who come to *know and* give care for children living with the virus. The counselors explained the reaction manifested through by saying *"Every one of our family are infected, no one is left for"* Others participant particularly grand parents say, *"I worked day and night by thinking I would save her ,the only one left ,she become one of them"* *"እቺ አንድ ፍሬ ልጅ እንኳ ትተርፍልኛለች ብዬ ነበር ቀን ከለሊት የምለፋው እርሷም ያው ሆነች፣ ዘራችን እኮ ብኩን ሆነ"*

Disclosure to Children Living with HIV

All participants acknowledged the importance of disclosure to children living with HIV. But still most of the children do not know their HIV positive status. The participants assume that they have disclosed partially to the children by informing them about the medication and treatment regimen which is uninterrupted and life long without clearly putting the name of the disease they are suffering from. These participants also made clear that age, failure to keep secret, fear of stigma and discrimination and *low maturity level of their children* are the major challenges which hinder them from disclosing to their children. One of the participant explain her fear and worries as follows,

> *How do I tell to my child that you are infected by the virus? (Crying...) If God allows us to live for long I will tell him his status when he becomes old enough. At this moment, what do I tell to a kid who can not differentiate good things from bad? What so ever I feel, I have to keep it with me. Otherwise, I will injure my child's psychology.*

Participants, who withhold their children's positive status from telling to the children themselves, reason out that, in the first place, the child is in a good status in relation to his lesson and health hence telling his/her HIV status might lead him to frustration. Others become very confused when they recall the issue of disclosing and say *"I have never and ever thought about it"* and others believe that if the child knows his/her HIV positive status, there would be a chance that every body knows both the parents and the child's status. They fear that this might affect their social life or relation within the community or in neighborhoods. Participants explain their interest to live with their neighbors with precaution and without having any trouble. They don't want to change or lose their neighbors' positive views, affection, closeness and even relations in 'Eders and Equbes'. So they prefer disclosing to their children until their children are able to keep a secret. They have also perceived that togetherness and respectfulness are pleasure in this world no one wants to lose. One of the parents explains she prefers to remain lonely depressed by her self rather to losing her neighbors greeting. She said:

> *I will wait a little longer till he becomes stronger .It is better for me to be anxious than telling him and seeing him go despair. I will wait until he becomes healthier, strong enough to handle it and until the right time comes. But still I am telling him indirectly to take precaution. I remind him if he bleeds, no one should touch his blood. I don't want to tell him right now, rather I want to wait until he becomes able to analyze things. At the same time, I don't want to disturb my peaceful relation with my neighbors.*

There were participants who explained that their children had already developed suspicion about their status. But they could not become sure since the parents and / or women guardians give various kinds of reasons for the illness and medication of the disease, like by telling them a heart disease, tetanus, nerve problem etc. Participants also respond that when their children become more suspicious about their status they ask a number of questions indirectly to get the right answer .One participant say that her child asks the cause of his parents' death since he had got information from neighbors about their HIV positive status and his status. At this time the response of the guardian was "*Do not call the name of this disease again.*"

There was another participant who was confused whether to disclose or not after hearing disgusting stories in relation to disclosure to children in mass media. When she was asked what her opinion was on the issue of disclosure to children, her response was "*I couldn't find answer for this question yet*"

There were some parents and guardians who have fully disclosed to the children. The children realized their HIV positive status in various course of events. There was only one case which the child was able to learn her HIV positive status through planned process (relatively). This participant was determined to test her daughter after briefly discussing in advance the side effect and complications of the disease with the child herself. The parent perceived that this will help them to develop confidence to test for HIV and accept what ever the result would be. The participant explained, when she asked her daughter for HIV test (since the daughter fall sick frequently), the response of the daughter was wishing the same result be found with that of her parent. According to this participant's response, after getting tested the daughter was in a better emotional condition than that of her parent. She was only 12 years old. The parent decided to get reassurance about the result and took her child to a private clinic for testing. The participant also added that she was glad about testing since if she had not been determined to test, she might have lost her daughter right away.

The other finding of the study clarifies the occurrence of accidental disclosure to the infected child at the time of post test counseling to the parent. This participant explain the situation as follows,

> *When I heard my daughter's HIV test result, I shouted and cried loudly. Unfortunately, my daughter (she is 14years old) was around the door and heard all things the counselor told me. When we returned back home, she asked, 'did they tell you I am infected by the virus?' I replied, they didn't, who told you such a bad news? However, she explained how she discovered her status. I couldn't be able to persuade her. I was astonished and started to weep bitterly again (crying...). This was the worst event in my life which I hadn't ever faced before. It was too hard to accept the result and even there was a time I attempted to commit suicide.*

The other participant explained that after watching television frequently, especially programs in relation to HIV/AIDS, her daughter (who is 11 years old) was able to know her own sero-positive status .She told to her mother that she had known her HIV status by saying "*I know why you gave me this medicine since I had got HIV from you.*"

Most participants and key informants have explained that mass media is playing facilitative role for increasing awareness level on the issue of HIV/AIDS in various ways, which includes opening a discussion floor for the professionals on the issue of disclosure to children living with HIV, teaching the mass about the medication (ART), provide general information about HIV/AIDS, experience sharing on the issue of stigma and disclosure, inviting role model peoples, and discussing on the experience and challenges of disclosure.

One participant reported that her child learnt his HIV positive status at school while he was playing with his friends. The child (10 years old) was drinking water by sharing same bottle with his peers. Among them one of the children warned both his brother and other children not to drink and eat with the same bottle and dishes with him by pointing out on him and said "*He is HIV carrier.*"

The other participant was forced to get the child tested since the initiative was come from the child herself. The participant said (crying …):

> *When my grand daughter who is 11 years old, begun to develop rashes and TB, she forced me to take her to hospital for HIV test. But the result showed her HIV positive status. When she asked me the result, I told her she is free from the virus. She become happy and began to kiss all of the family members. But, after few days when I started to give her medicine, all her pleasure has gone for good and said 'Is this the medicine which I am going to take? I know it, it is ART.' After that she started to cry and said 'I felt that I could not live for long.'*

Another participant explained that her child had identified his sero-positive status by himself. When he became 14 years old, he started to take the medicine by himself and read the instructions found on the packet of ART tablets. However, one day he took the packet to the nearby pharmacy and asked them to sell similar medicine for him. But the pharmacists told him that such kind of medicine is not for sell rather obtained in the government hospital for HIV patients. After returning back home, he told to his parent with crying how he identified his HIV positive status. But his parent became very angry on him.

The response of participants implies that even though almost all children, who knew their status, did not learn their sero-positive status by the help of their parents and guardians they clarify that the children primarily went and discussed with their parents and/or women guardians about the certainty of their sero-positive status.

Even if all of the participants agree on the importance of disclosure to children living with HIV, there is variation in their suggestion on the age of disclosure. Above half of them prefer to disclose at the age of twelve, the rest favor above the age of fifteen. The first group justifies children at the age of twelve starts to analyze things in a better way, so it is preferable and appropriate age to disclose .Until then, it is important to discuss with them about diseases in general. The latter group justifies that children at the age of fifteen show behavioral changes in relation to their sexual behavior. Therefore, it is mandatory to disclose in order to prevent them from being re-infected and infecting others. One participant, who is in favor of this group, further explained that age of disclosure to children varies from male to females. She said:

> *Females are very much active and exposed to sexual activity at the early age than that of males. Therefore, the age of disclosure to female children should be by considering these factors.*

None of them agree disclosure before 6 years of age since children at this age could not even pronounce words properly and understand what disease, life and death is. The counselors also share all the above ideas but they express their challenges while working with parents/guardians on the issue of disclosure especially with those who have children of ages between 16-17. They explain that the national guide line for pediatric HIV/AIDS care and treatment assumed that children knew their HIV status until the age of 15.Because children, who are above 15 years old are considered, treated as adults and can get HIV blood test without their parents/guardians consent. But in reality parents and guardians are reluctant to disclose even at the age of 15 and above.

Some participants replied similarly by saying that disclosure has to be done gradually and slowly without damaging the psychology of the children based on their development level. There were participants that had same opinion just like others on disclosure to infected children .But they suggested, it is better not to tell if the children are young and unable to keep secret. If they have reached at the stage which they can keep secret, it would be better to tell and discuss with them. Otherwise, when they discuss with friends about their own status, there will be an implication on status of the parents and other siblings. All this would lead to spread of the family secrets. Therefore, it is better to just give the medication without telling them till they get matured enough to understand or handle the situation.

There were very few participants who respond that their children did not have hint about their HIV positive status. Among these participants one guardian explained that she had assured her children that they are free from HIV. This happened while taking all of her children including the infected one to hospital for HIV testing by giving pretext for going abroad. Then she told to all of them that they are free from the virus.

The responses obtained from counselors also support all the above mentioned information. In addition, they say when most parents/ guardians come to hospital with their children; they tell to professionals "*since the child doesn't know his /her status, please don't talk about HIV/AIDS when I come with him/her.*" From their responses, it can be inferred that the counsellor's experience on disclosing in a planned manner (after giving on going counseling service) was less since parents do not discuss the issue of disclosure with them. One of the counselor nurses say "*except in very few cases parents/guardians didn't ask for help on disclosure issue.*"

From the over all responses of the participants it can be said that in this study, there is pattern of disclosing to children living with the virus. Some of them have partially disclosed, others fully disclosed and the rest have not disclosed to their HIV infected children.

Sentiment of parents and guardians towards Disclosure to Infected Children

Those participants who disclosed to their children reported that they have experienced a completely contradictory feeling. They feel pleasure and relief since the children had learnt their positive status .These participants *have* perceived that even if they die, their children will take the medicine regularly since they knew the severity of the disease. On the contrary, they also feel anxious for the reason that their children are suffering from fatal /deadly disease.

There were also participants who have disclosed to their children but totally feel desperate about both the disease and children's realization of their own positive status. This was because the children had learnt their status without the interest of the parents and/or women guardians and ,at the same time, had lost interest in taking medication due to the fact that it has to be taken through once life time. One of the participants explained her sentiments as follows:

> *I feel sorrow when I see her because she lagged behind from her peers due to the disease. Her development is so slow. She can not do whatever she likes. Some of her peers say that their parents had told them not to play with her so they don't want to play with her. As a result of these and other things, I don't feel good.*

According to the participants who did not disclose to their children, they feel depressed even though they recognize the importance of disclosure. In contrast, there are other participants who feel happy for not disclosing to their children since they perceive that the children are too little to understand the concept of disease, life and death. Furthermore, their justification for non-disclosing to their children is to protect them from being torched, insulted and pointed out by others. One participant put in plain words her reason for non-disclosure as:

> *I feel so distressed by myself since I twisted my life. Further more, with out knowing any thing he should not deserve to be punished for what he has not done. I am not happy. When I think about his status, I am in dilemma and I feel much more depressed myself. I am also frightened about the other children since they have not tested. All the time, my mind is restless in thinking of his illness and feels disappointed.*

The counselor nurses explained from their experiences that even if some parents have knowledge about on how to disclose to children living with HIV, they refuse to disclose due to various reasons. Even after a continuous counseling session with them, there are some parents and guardians who are not willing to discuss the issue of disclosure to the extent that they do not want to mention the name HIV/AIDS in front of their children. But, according to counselors, they encourage parents to investigate the awareness level of children by asking some questions before disclosure like:-

- What do you know about the disease?
- What do you know about HIV/AIDS?
- What are the transmission ways of HIV/AIDS?
- What happens on HIV patients if they didn't take properly their medication?

Who Else Know the Sero-Positive Status of the Children?

All of the participants of the study were asked who else know about the sero-positive status of the children? Most participants explained that family members (including siblings), relatives and neighbors knew. One participant explains how her son knew about his brothers HIV positive status:

> *My elder son knew his younger brother sero-positive status. This happened when I heard about my child's statues, where I was very much disturbed and unable to calm down. I had also stared to talk with myself. Since he was with me, he had listened all things what I have said.*

The other participant stated that all the neighbors identified the family's positive status before the family knew their own status. As a result they openly insult the children by saying "*You carriers.*" No one is also willing to use and share materials with them and not interested to enter their home.

The rest of the respondents explain in addition to their family members, neighbors and relatives also know the HIV positive status of the children. Their response shows that some of them receive a positive approach while others are still facing stigma.

> *I know how much we were stigmatized in our previous living area, denied neighbors' greeting and isolated. Now, even if my parent returned from grave, I would not tell to her.*

Only very few participants respond that no one knows the status of the children except themselves. As they clarified, their reasons were to protect the child from gossip and insult by others.

Third Person Involvement in the Process of Disclosure

Participants were asked if they suggest the involvement of third person at the time or at the process of disclosure. All of the participants those who did not disclose prefer at the fist place their own presence; moreover they need the help of God together with that of the health professionals. One participant said:

> *Personally, I wish no one to be there except the health professionals, me and my Lord. Because mostly secrets are kept for long when people who knew about the issue are very few, otherwise it might leak.*

One parent added that if she had a daughter she would have allowed her to get involved on the process since females are more reliable to keep secret and take the responsibility of child rearing practice after the death of parents.

Parent-child Relation before and after Disclosure

At the interview, all of the participants were asked the kind of relationship that exists between parents and / or women guardians and children. The response showed that even if all have intimacy with their children, the degree of closeness differed from one to the other. The entire participants who did not disclose to their children responded that they could not guess about the future (after disclosure what will happen). Among these participants, some are sure that their intimacy will increase, others report their anxiety "*he might hate me*". Some say "*I fear she might avenge me.*" one participant said "*We* *don't have a closes relation with each other since we are not happy in our life.*" and other participant said "*no change is seen till now.*"

Most participants who disclosed the sero-positive status of children have developed a good relationship after disclosure. Some of their statement presented here as:

> *Before he knew his status, the entire family member considered him as a newly born baby. So I and other family members were doing every thing for him. But now he considers himself as an adult and wants to take care of himself. I also advise him that knowing yourself means saving others from infecting by the virus so take care of yourself and others. Furthermore we all havegood parent-child relations with him but he tries to isolate himself rather to have intimacy with his friends*

Illness Management

The second specific objective of the study was to assess the situations of parents and/or women guardians on managing the illness of children living with HIV.

Response of Parents and Guardians to questions raised by children

The finding of the study revealed that children raise various kinds of questions in relation to their illness, medication and treatment regimen. But the kind of question inquired by children those who know and do not know their HIV status are different. Most children who know their sero-positive status inclined to get more information and learn from various sources like through mass media and reading, but still there was one child who knows her status and raised astonishing question and felt very bad about herself especially when becoming sick/ill. The participant reported what do the child said as:

> *She inquires questions especially when she becomes ill 'Why our Lord gave this disease to us only? What sins did we make? Why?' She also says, 'Why doesn't he take away my life now? I don't want to live in this world any more' and she becomes annoyed and weeps. My response would be God doesn't give this disease only for us. There are a number of people who are living with the virus. They feel healthy because they don't worry too much about their illness. They simply eat,*

> *drink and take their medicine properly. But they don't want to tell their status to others. So, don't worry, one day our Lord will give us his mercy and we will be healthy, but until that day comes we have to be patient.*

The other parent explained her child's expression as follows:

> *What would you say if the doctor tells you that I am free from the virus?" At this moment, I become very much disturbed and kept silent.*

Those children who did not know their status or get an appropriate response raise similar questions repeatedly. The findings also show that, there are children, both from disclosed and not disclosed, did not ask any kind of question in relation to their illness.

The feelings of the participants are divergent; some feel deep sorrow, guilty; weeping, anger, few feel nothing since they have strong religious believe that they will be cured by God, and others become emotionally disturbed when the children ask question in relation to their medication or poor health condition. But their responses are similar like *"you are taking the medication not to relapse the former illness"*

According to the respondents and health professionals, the kinds of question which are asked frequently by children especially those who did not disclose are:

> *Why the nurses take blood from me? How do I come to hospital in this (ART) unit? Am I taking the medicine not to be sick again? Why do I take tablets and get HIV related medication like CD4 count? What will happen if I didn't take the medicine daily? Will I die just like my mama and dad? Do I have lost my parents by HIV/AIDS? Why the medication is not interrupted since we are healthy now? For how long do I am expected to take the medicine?*

From the key informant interview and participants response, it can be inferred that parents mostly did not give the appropriate response for children's request rather inclined towards deception. The response of one participant in this regard can be read as:

> *Frequently, my daughter who is 9 years old asks 'why do I take tablets and get HIV related medication like CD4 count?' Since I do not want to let her know that she got HIV, I persuade her that she is taking the medicine to protect her ear from bleeding. But I always feel distressed when she asks me suck kind of questions".*

Another participant explained that some times she would buy cough syrup for all of the family members to take it constantly (8-10days) so that her wards do not forward any question and develop suspicious about their status. She clarifies that this will help the children especially those who take ART not to feel *"why only we take medicine?"* Furthermore, she also didn't allow them to go far away from her and communicate with other children, while going to hospital for collecting drugs .Because she fears other children who know their own positive status will tell her wards. She has also posted HIV positive children posters in her house. She explains that, the availability of this picture helps the children to see it as a normal picture. She had a strong belief that one day God will cure them. She remind that one day she took both children to hospital for HIV test since she saw a number of improvements on their health condition but the result was the same.

Children's Reaction in Taking Medication and Visiting Hospitals

From the response of the parents and guardians it was found out that there were very few children (one disclosed the other not disclosed) refused both to take their medication and visit hospital. As a result of this, quarrel with and punishment for the children become common phenomena in their house. One of the participants explains that her child did not have interest to take the medicine any more, so she says *"Am I expected to take these tablets throughout my life? If it is so, it is really very tiresome.'* As a result, she is totally unhappy. At the time of visiting hospital, she also says *"If both of us bring the medicine on this month, by next month I don't want to go there. You can go to bring it."*

Some participants who have disclosed and non-disclosed children explain that their children refuse either in visiting hospital or at the time of taking medication. These children start to cry when looking the hospital from out side since they had been admitted there for long period of time. Other children do not want to take medicine since it was changed from syrup to tablets. There were also children who get frustrated by taking the medication since it has to be taken through out life time .As a result, they say, *"I need some rest from taking this medicine"* or they ask their parents and guardians "*please skip today."*

The response which is obtained from key informant interview show that there are parents who complain that their children become nervous when they are reminded of the appointment date to go to the hospital, or they try to skip it by saying "*Today I will not go there since I have an exam or test at school."*

On contradictory to the above mentioned responses, there are other respondents who say that their children are very much obedient both in taking medication and visiting hospital. One participant reported that:

> *There is a big difference in taking medicine before and after knowing his status. He has a good feeling in taking medicine and visiting hospital right now. When the time for taking medicine reach and if there are people around us, he would remind me by using his code system.*

The other participant says:

> She never gets tired with her medicine and even the timing. Some times I went out from home purposely and looked at her from out side whether she takes her medicine on time or not. But still she takes it exactly on time. She has understood that it should be taken on time and continuously without stopping. She never misses her timing. If she is playing she will tell to her friends she has to use the toilet and runs in to the house to eat something before taking it. She has adapted it very well. She takes it with great eagerness feeling. She is willing to come to hospital.

Social Interaction and Behavior of the Children

The data were collected with regard to the behavior and social interaction of the infected children. The response showed that regardless of knowing their own status, the children have diverse behavior. The report shows that most participants explain that their children are aggressive, nagging, keep silent, doesn't have a cooperative behavior, always quarrel, isolate him /her self, become negligence, silly, does not want to concentrate on his/her studies, careless, and do not have strong social relation. On contrary to this, there are also parents and guardians who say their children have an excellent social interaction, live a joyful, and healthy life. The response of the participants can be put as:

> *I don't know whether it is his normal behavior or the effect of the disease. He is so aggressive and annoying boy. Sometimes I consider his act to be the side effect of the tablet he takes. He does things restlessly. Mostly, he does things that you told him not to do. But he plays too much peacefully with every body. He does not give much attention to his studies. And this scares me very much. Nonetheless, the way he thinks is smarter and better than his elders. I can say that God did not leave me with two troubles at a time.*

The other participant says:

> *My son has a good social interaction with all of his friends. He has many friends but the number of females is larger than that of males. So I always advise him to take care of himself from having sexual relation with them. He is very funny and happy boy. He regrets too much when he reminds that he is unable to go abroad so he says as a fun "just like 'Waliya Ibex' I live only in Ethiopia."*

Another participant explained as follows:

> *She lives a joyful and healthy life. Her behavior is normal .She doesn't mind or don't get obsessed with things. Sometimes I smile watching her smiling without knowing the reasons. Simple things make her smile. She likes art, draws beautiful drawings in her free time, and likes to dance different cultural dances. All these things make both of us happy.*

Cues to Disclose

The third specific objective of the study is to assess the cue factors which motivated parents and guardians to disclose or not disclose to HIV positive children living with the virus.

Discussion and Counseling on HIV/AIDS

The report of the study illustrates that there is open discussion among most families who participated in this study. Other than this, there were few participants who responded that since they have disclosed to their children, they chat not only about the disease, its medication and treatment regimen but also about the children's future life, education and carrier. Some participants reported that there is no discussion on the issue of HIV/AIDS in their family at all due to fearfulness of considering it as taboo, worrying that the child will suspect about his/her status, the child is too little to understand what AIDS is and tell to his friends or others openly (leakage of family secret).

Almost all the participants replayed that, mass media (Television and Radio) are the major initiatives and motivating factors for the dissuasion of HIV/AIDS among the family members. There are participants who said that, *"Since the children are taught about HIV/AIDS they have much better knowledge than us. Therefore, they tell us what they have learnt in schools."*

Above half of the participants speak out that they did not regularly discuss with health workers about the issue of how, when, and what to disclose to the children. Participants make clear that the professionals have no time (too busy) to discuss with all of them. Few participants discuss with the professionals when their children refuse to take the medications regularly or are not willing to come to hospital.

Almost all of the participants respond that their children did not get a counseling service from the hospital due to some personal factors like fearfulness of the parents that the child will suspect his /her status and due to professionals / counselors tight work load.

The observation and experiences of the professionals indicate that there are very few cue factors which initiate parents and/ or women guardians to disclose the sero-positive status of the children like the maturity level and age of the child, frequently raising questions by the child side, lack of adherence toward medication, suspiciousness of the child, rumors from neighbors, etc. They also added that children might identify their own status by themselves but they need assurance from the one they love and trust. So they said to their parents/guardians "*Even though you withhold my status, I have realized that I have HIV/AIDS*". By this time, most parents become terrible and say "*How do you know?*" "*Who has told you?*" The child tells to their parents/guardians that "*Tell me the truth, I have seen on Television peoples who have HIV/AIDS and are taking medicine which is similar to mine. Am I infected by the HIV?* After these moments, parents and guardians realize that the child had known both about the disease and his/her status so they disclose to the child.

DISCUSSION

Experience in Disclosure

In this study most of the participants were parents who believed it was their responsibility to disclose the HIV positive diagnosis to their children living with the virus. The findings illustrate that HIV positive children were adopted by guardians who again entails the importance of extended families for the provision of care, support, and treatment for children infected by the virus.

All of the participants have basic knowledge on HIV/AIDS like its transmission and prevention. One of the advantages of knowing the mode of transmission and prevention is to minimize the possible stigma and discrimination the patients might come across with.

The findings show that the mechanism how all respondents had learned the positive status of their children was various. However, basically all of them were related in one way; when they went to hospital for treatment after the children fall sick severely. If HCT is easily accessible for every one and awareness toward the service is high, it could help parents and guardians to initiate testing their children easily before children fall sick. The awareness level of the community at large also affects testing for HIV treatment and prevention, especially for children. The experience of one of the participant show how she challenged even by the health professionals to test her child's since at that moment HIV testing for children was rare.

As the findings illustrate, there were three types of experience in learning the HIV positive status of children. These experiences show the different level of understanding and readiness of participants towards taking remedial action for the illness of children.

In addition to the above findings, there was an incident that one parent was able to learn her child's HIV positive status after the child started ART. This exemplifies even though professionals had kept the confidentiality of the information to others particularly to the child's aunt, they fail to disclose to the parent on time. This has its own impact on the parent to manage the illness of the infected child, to accept the diagnosis easily and disclose to the child.

The other findings showed that pre and post counseling services to parents about their child's positive status is pertinent issue which has to be given greater emphasis by the counselors. Counselors are expected to keep the best interest of their client in addition to confidentiality issue. But the finding of the study shows violation of ethical consideration of the client. Since the client's child learnt her sero-positive status without the consent of the parent, it suggests the counselor's ignorance toward the confidentiality issue of disclosure.

From the result of the study, it was apparent that the respondents' reactions when realizing the status of their child vary from person to person. Such kinds of reaction could reflect their expectation toward the result and anxiety to the disease by itself. But those who did not expect the result sometimes become happy about the diagnosis even though their pleasure is not truly due to being infected by the virus but only by getting relief as a result of only knowing the exact cause of their children's pain. On the other hand, their reaction could be as a result of hearing bad news. But it does not mean that bad news always result in bad feeling, some times it brings a feeling of relief from being worried about it all the time.

From the findings, it was investigated that all participants recognize the importance of pediatric HIV disclosure, at the same time, the challenges surrounding this process. This shows the complex nature of discussing HIV status to infected children. The findings show that most children (whose parents and guardians participated in this study) did not know their HIV diagnosis. Consistently, according to the American Academy of Pediatric (1999), the study which was conducted in America showed that 90% of the participants did not disclose to their children.

The findings of this study showed that few children knew their HIV positive status. Unfortunately, all of them did not get appropriate counseling service before and after disclosure and was not disclosed by their parents or by counselors in agreement with their parents and guardians. Rather, they became familiar with their HIV positive status at different events and/or by their own efforts. Ledlie (2002) states that unintentional disclosure, where children find out by overhearing conversations, from other individuals already privy to the information, or through self-discovery, can undermine the child's sense of trust in adults.

In this study, there is a clear difference between the age at which disclosure actually occurs and at which participants prefer disclosure to occur (approximately 12 years of age) .This is consistent with the study conducted in South Africa by Moodley K., Myer L., Michaels D. & Cotton M. (2006) where the child's age is found to be a key predictor whether or not disclosure to occur. This preference requires further research and attention. If documented more generally, it may deserve attention from health care providers working with infected children and their families.

This study shows the presence of patterns of disclosure to children living with virus, like partial, full, and non-disclosure. This finding is exactly similar with the summary of finding of Wiener.L, Mellins.C, Marhefka.S, & Battles.H (2007).

The findings of this study show that there are many challenges and influencing factors which participants mention for not disclosing to their child. Hence, it can be suggested that this challenges could be observed from three different sides which include the parent's, the child's and the professional's side.

From the parent's side, the mode of transmission of HIV to children through MTCT is above 90% (WHO, 2007). As a result, they feel guiltiness, blame themselves, and anger about the positive status of the child and prefer not to tell to the child. Parents might fear that disclosing to the child would raise the question of how the child and the parent become infected by the virus. These kinds of questions may not be comfortable for parents, therefore consciously or unconsciously parents do not want to mention even the name of the disease or virus. These ideas were supported by the American Academy of Pediatrics (1999). Parent-child relation might also be another challenge for parenthood. Parents may not have close relation to their children to discuss openly; as a result, disclosure becomes a big challenge for them. The last challenge can be family dynamics. Considering complexity of family dynamics is important before deciding to disclose. According to American Academy of Pediatric (2002), parent/s that are emotionally unstable, experiencing significant anger or guilt about the infection are not ready to allow ongoing discussion about the virus since some children could not able to keep information confidential. In such circumstances, the disclosure of diagnosis could lead to serious financial, social or even psychological threats to the family. Therefore, parents prefer to delay disclosure until a time when family's wellbeing will not be jeopardized or the child is developmentally capable of keeping information confidential. So they choose the child not to know or even suspect his/her status and give a fictitious response for the children's question in relation to their illness.

On the child side, age and psychological development of the child is the first challenge for parents and guardians. Since they might believe that younger children could not differentiate good things from bad, as a result, they might tell their status to others and secret of the family would leak out. This idea is supported by the American Academy of Pediatrics, (1999) and Sandra, (1999). In addition, parents may perceive that children should not be involved in discussion particularly on HIV issue because of their small age. The study conducted in Ethiopia by Meron (2006) and Kedija (2006) show that, the participation of children in decision making on any issue is not much. Mostly their feelings are dominated by their parents. Parents and guardians also consider their ideas and suggestion as worthless since they perceive that children do not have the capacity to analyze things due to their little age.

From the finding, the last challenge for disclosure resulted from lack of appropriate and on-going counseling service from the health professionals' side for the children and their parents. This problem has its own influence on participants' decision of disclosure. All the above mentioned triangulated challenges are intermingled; therefore, it is impossible to differentiate one from the other.

In addition, the cornerstone for disclosure of child's HIV status to him/her is the parent's decision making which intern depends on their belief towards the issue, as found out in this study. In this study, all of the respondents even if they do believe on disclosure, preferred to postpone the issue of disclosure.

The qualitative findings of this study show that several challenges are associated with the participants' decision to disclose or not to their children living with the virus, such as age, maturity level of the children, fear of the subsequent stigma, family dynamics, blaming oneself, etc. The same is true with the summary of different findings analyzed by Wiener,L; Mellins,C; Marhefka,S; and Battles,H; (2007). These show how the issue is challenging for parents and guardians and controversial for health care providers.

In relation to intimacy between parents and guardians and children before and after disclosure, the finding shows that most of the participants have threat about the future relation since they perceive that the child might hate, annoy or avenge them when he or she knows his or her HIV positive status. There is similar suggestion by the American Academy of Pediatrics (1999).

Even if the literature found from the American Academy of Pediatrics (1999) states that parents who disclosed to their children feel relief than those who did not disclosed, in this study, there are mixed results in relation to the parental and guardian sentiment to their decision to disclose or not. In spite of the children's familiarity about their own positive status, parents ironically feel sorrow and pleasure. Therefore, this area needs further investigation by other researches.

The finding also shows most of the participants prefer their own involvement in the disclosure process or to be the best person to discuss the diagnosis with the child with a great support from the professionals. A study conducted in South Africa (Moodley, K; Myer, L; Michaels, D; & Cotton, M., 2006) also shows similar result. If possible, parents should be the ones to disclose HIV result to their children. This finding implies that parents did not have enough knowledge on how to disclose and how to handle the emotional experience associated with disclosure. They need practical support to understand how to explain the results to their children.

This study finds out that most participants tell to siblings, relatives and neighbors the sero-positive status of the children. Even if disclosure to public has its own demerits, it can be said that parents can receive counseling and other supporting environment from their close relatives and school teachers.

Illness Management

In this study, most of the children (9 out of 14) are willing to take their medicine and visit hospital regularly. But this finding is totally different from the summary of the finding of Wiener.L, Mellins.C, Marhefka.S, and Battles.H (2007) which shows the presence of mixed finding on the impact of disclosure to their adherence in medication and visiting hospital. The children's willingness to visit hospital and take medication could result due to the fact that most of the participants in this study use different mechanism like giving praise (candies, soft drinks or chocolates) so as to initiate the children to take medication and visit hospital. Unfortunately, because adherence was not a primary focus of this study and did not more thoroughly examine the interplay between disclosure and adherence to medical treatment, therefore, it is difficult to draw solid conclusions or make recommendations on this issue.

The finding of the study show regardless of the pattern of disclosure, above half of the children have both the internalizing behavioral problem (isolation, depression anxiety and withdrawal), externalizing behavioral problem (attention problems, aggression, and conduct) and also have poor social interaction. Even though the culture, economic status, places and time with which the research conducted is different, a similar study conducted in India showing most children (26 out of 35) reported stressful experiences due to learning their HIV status regardless of the disclosure patterns (how they were told) (Schonfeld, 1997).The other similar study from Mildmay in Uganda indicate that many HIV infected children are not told of their HIV status. Depression among these children (and even those who knew their result) often goes unnoticed and untreated (Tindyebwa D., 2004). It can be suggested that let alone for the children the issue of HIV/AIDS and its illness is very disturbing for adult. Not getting a supportive environment could be one factor which makes children manifest such behaviours. In another way round, inability to adapt the medicine and treatment could also be another reason; the secrecy of the parents withholding the illness status, and failure to get ongoing counselling services might influence their behaviour.

Most children ask questions which are related to their illness and medication. This indicates that children are not simply passerby but either they already knew the diagnosis and are keeping secret or waiting for parent to tell or they may express by different reactions including refusal to regular visits or drug intakes. This idea was conformed by ICAP's (2003) report that children sense when something is out of ordinary, silence and secrecy can deprive them of the opportunity to explore their emotion or fear and ask relevant multitude questions.

On the other hand, the answers given to their questions are crucial to achieve good relationship or trust with their parents and guardians. Unfortunately, most participants fabricate wrong reasoning other than approaching to the right way. This is exactly what resulted from this study.

Cues to Disclosure or Not Disclosure

There is loose communication between parents and guardians and the counselors, due to work load and large number of clients getting service in the hospital. These situations have significant influence on disclosure by parents and contribute to the parents' and guardians' decision to retreat from disclosure.

The finding clarifies that media play a major role in creating awareness on HIV/AIDS and initiating people to discuss with their children and family on the issue.

Even though Media's role in creating awareness for the community on HIV/AIDS is highly promising, on the other hand, it is exposing those who are taking the medicine to be stigmatized. Moreover, the programs which are transmitted in the media are mostly not target-oriented which lead to the unplanned disclosure to children especially showing drugs.

Conclusion

The study reveals that majority of the participants were parents who have HIV infected children. They were able to know sero-positive status of their children after the children had fallen sick .Participants were initiated by the health professionals to get HIV blood test for their children. Their reaction and feeling when they heard the diagnosis of their children was very diverse. Some of them wept bitterly, and blame themselves, while others were depressed and attempted suicide.

Even though participants acknowledge the importance of disclosure, most of them did not disclose to their children since they face perceived and real threats from the children side, their own side, health professionals' side and surrounding community (stigma, discrimination and rejection) at large. As a result, most participants decided to postpone the time of disclosure to the children living with the virus. Yet some of the children learnt their sero-positive status without the fulfilment of preconditions for disclosure like parents consent and health professionals' support and involvement. This shows how much the issue of disclosure is difficult and challenging.

Even if it is perceived that parents who fully disclosed to their children have better psychological outcome than those who did not disclosed, the result does not support this idea rather show a blurred vision which need further investigation.

Regardless of knowing their HIV positive status, the children show poor social interactions, internalized and externalized behavioural problem. Paradoxically, they are cooperative in taking medication and visiting hospital. Since their parents and guardians provide various kinds of praises.

Children raise various kinds of question in relation to their medication and poor health condition. However, the responses forwarded from their parents and guardians were full of deception, lie and anger.

In summary, this study highlights the growing importance of pediatric HIV disclosure, particularly, in the context of the scale-up of HIV treatment and disclosure services in many parts of our country. Greater attention to issues of disclosure of HIV status to infected children may contribute to the improved quality of long-term care for these vulnerable populations.

Implication to Social Work Practice

The main objective of social work is empowering individuals, families, groups and community. It enables people to make use of social resources .This approach of empowering practice incorporate the basic values of National Association of Social Work Code of Ethics (Gutierrez parsons, and Cox, 1998) .Hence several commitment outlined in the code are particularly important to this practice. According to the above writers, the social work practice frame work contains values, sanctions, a theory base, a professional relation ship and an organized frame work for identifying and assessing social problems, planning strategies intervention and evaluation.

The practice takes place in many different contexts in voluntary and statutory agencies, individually and in private practice, in education, at work, in medical setting, in religious institutions, etc. In addressing problem, there are three multi system levels micro, mezzo, and macro. These levels are interrelated and interconnected .Disclosure to children living with HIV/AIDS is not only left to grass root or at individual level but it demands the involvement of policy makers at macro level, multidisciplinary team work at mezzo level and parents, individual and family at micro level. The study focuses in all these levels. To this end the following social work interventions are proposed.

The issue of HIV disclosure to children living with HIV has to be given a greater emphasis in collaboration with that of an on going counselling service for parents and guardians who have HIV positive children and the children them selves.

Disclosure should be done individually to involve the child's cognitive ability, developmental stage, clinical status and family dynamics. This approach could be achieved through provision of an on going counseling for the children and their families. The intention of counseling should help children and their family to cope with their emotions and challenges they experience as a result of being infected with HIV. Such counseling helps children and their family to adopt a positive living attitude. This in turn can help them to prolong their life, and improve their quality of life.

As the social work code of ethics necessitates interaction with the child, it should take place with the presence of parent or other family members until the counsellor gained the confidence and trust of both the child and family .Another advantage of the presence of family member is that it enables the counsellor to observe the reaction and interaction of both the child and family.

Social work practice in paediatric disclosure needs to assess the children's psychosocial needs, family system, and support structure. Psychosocial assessment of the child's need should consider the child's function and developmental stage, education, school based needs, peer relation, CD 4 count medical issues and concerns, personality and way of adjustment to living with HIV /AIDS. Assessing the family system has to given greater emphasis for the norms, values, beliefs, and socio-cultural dynamics of the community, religion or level of spirituality, and financial stability of the family welfare, needs, present family structure, regularity of the care provider, family capacity for supporting adherence to ART regimen, and stability of the family has much effect on the lives of the children. Lastly, in making assessment of supportive structure, the extended family and the community support system has to be considered.

In terms of group approach parents and guardians could benefit if they organize themselves in the form of voluntary based self-help group. Establishment of the group can help them to share their experiences and challenges in disclosing to their child. This approach can help them to identify their strengths. In addition to this, it is possible to organize children living with HIV to create peer counselling group to share their experience, learn from others coping mechanism for the existing stigma and discriminations.

Social workers, HIV support groups (individuals of HIV/AIDS related health care providers), and various organizations in favor of HIV infected children can collaborate to advocate disclosure of positive status based on their cognitive ability, developmental stage, clinical status and social circumstance by awareness creation to the family and guardians.

A supportive environment for HIV infected children and their families could be created by raising awareness through advocacy and social mobilization. HIV infected children are frequently victims of stigma and discrimination, hostility, isolation and human rights violations. To this end, various NGO's in collaboration with stakeholders could possibly have to play a role in awareness raising and social mobilization to build a more supportive environment. Intensive advocacy work should be carried out at national, regional and local level to sensitize concerned government officials, opinion leaders, religious leaders, and others to enable them understand the severity of the problem. The care and coping capacities of families and communities could be strengthened. Responses to the needs of HIV infected children come from families, extended families and the community at large. Therefore ,strengthening the capacity of families and extended families to fill the widening gaps in the safety net traditionally provided by the family and extended family may be the most cost effective, efficient and sustainable way of assisting children Living with HIV.

There should be the involvement of children living with HIV in all process of provision of care and support for their illness status as part of the solution. Children are not simply a passive, powerless target group to be aided, but capable actors and important resources to engage in disclosure issue and other health related problem.

The findings of the study have a great implication for social work practices in area of policy implementation through awareness creation particularly for families and guardians. The national guide line assumes that, children above the age of 15 have to be informed their HIV positive since they are considered as adults and also children 13-15 years old have the right to test for HIV without their parents/guardians consents since they are "mature minors". But it has to be clear that at policy level, it is impossible to forward specific age of disclosure because disclosure is a personal decision and human right issue. In addition, it is also important to remind that there is individual difference among children.

The macro level of intervention in this study could be advocacy on four-pronged approaches of PMTCT. The strategy of advocacy could be achieved through awareness creation on 1) primary prevention of HIV infection for females; 2) prevention of unintended pregnancies in HIV infected women, 3)prevention of HIV transmission from infected women to their infants and 4) Treatment ,care and support of HIV infected women ,their infants and families.

A multi-system approach to disclosure can help families assess the various systems which impact their lives so that they can identify obstacles and locate sources of support. Multi-system levels include the individual child, parent-child relationship, siblings, extended family and non-blood kin, relationships with health providers, schools, community, religious institution, child welfare, legal services, and other social systems. Providers can assist families in identifying concerns, needs, and strengths of the child, risks related to stigma and discrimination within the school or community, supports within the family, at school, within the community, and legal resources.

Finally, rather than focusing only on families and health professionals to create awareness toward the disease and its complication, it is possible to work for the incorporation of HIV AIDS education in curriculum for early school age children.

Implication to Research

Since children continue to be born with HIV infection, and disclosure of HIV infection to children remains a pertinent issue in settings where the numbers of children living with HIV are unfortunately high, a longitudinal research is vital for understanding right issue. In addition, it is also important to remind that there is individual difference among children.

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Implication to Research

Since children continue to be born with HIV infection, and disclosure of HIV infection to children remains a pertinent issue in settings where the numbers of children living with HIV are unfortunately high, a longitudinal research is vital for understanding the processes of disclosure. Studies have to be designed to flush out factors that promote or hinder disclosure, psychosocial impact of disclosure, communication between children, parents, and health care providers. Additionally, it needs a better understanding of how to develop and evaluate interventions that promote disclosure of infection to children.

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Annex I

Consent Form (Participants of the Study)

Good after noon! My Name is _____ from Addis Ababa University graduate school of Social Work. I am doing research, the topic of the research is "Disclosing HIV Positive Status to Children: Challenges and Experiences of Mothers and/or Women Guardians from Zewditu Memorial Hospital.Therefore, objectives of the research are to explore experiences of mothers and/or women guardians toward disclosing HIV positive status of children, to assess the situations of mothers and/or women guardians on managing the illness of children and to find out the existing cue factors that motivate mothers and/or women guardians to disclose or not.

Your responses for the questions should base on the experiences that you have faced to disclose or not to your child. Therefore, there is no right or wrong answer. In the interview, I may ask some personal questions that might be secrete or difficult to answer. However, I would like to assure you ahead that your responses will kept confidential. On the report, there will not be information and means that will be identified and your responses. Your responses will used for this research purpose only. Furthermore, if the result of this study published only the information of the total group will appear.

Only volunteers will participate in this study. However, your participation and non-participation will have no effect on the service that you receive from any service provider. You may end the interview any time you want. Your honest answer to the questions will help the researcher to understand better the problem. So feel free to express your feeling and opinion. In order not to miss any points from our discussion, I will use tape recorder. To this end, your cooperation in responding the questions has had a paramount significance contribution toward the success of the study.

Would you like to participate?

Yes No

Name _________ Date ___________ Signature __________

Thank you, for your willingness!

Addis Ababa University

School of Social Work

Interview Guide for Participants of the Study

I) Socio-Demographic Characteristics

1. Parent/Guardian

1.1) Age: ________

1.2) Educational status

Illiterate ___________

Elementary Completed ________

High School Completed ________

Other (specify) ________

Read and Write ________

College diploma ________

College Degree _______

1.3) Occupation:

Government Employ_______

House Wife ________

Other (specify) ________

NGO Employ ________

Merchant ________

1.4) Religion

Muslim _______

Orthodox _______

Other (specify) ________

Catholic _______

Protestant ________

1.5) Marital Status

Single__________

Married__________

Widowed_________

Divorced _________

1.6) Relationship to the child

Mother _______

Guardian _______

Father ________

other (specify) ________

2. Child

Sex: _______

Age ________

Educational status ________

I) INTRODUCTORY QUESTIONS

1) Tell me some thing about your family and social life condition.
2) How do you describe your health seeking behavior?
3) What do you know about HIV /AIDS?

II) Experience of Disclosure

1) Let me ask you how you learn the HIV positive status of your child. What was your reaction and feeling at the moment?
2) Does the child know about his status? When? Why? What happen latter?
3) Let me ask you the kind of sentiment and attitude towards disclosure you have?
4) Whom do you relay on to help you to disclose the sero-positive status of your child? Why?
5) Who else know about the HIV status of the child? Why?
6) Let me ask you, how do you evaluate your relation with the child before and or after disclosure?

III) Illness Management

1) Tell me about the kind of question that the child raises in relation to his/her illness? How do you feel about it and how, what do you respond to him/her?
2) How do you describe the experience of the child in taking medication and visiting Hospital?
3) Let me know the kind of social interaction and behavior the child have.

IV) Cues Motives to disclose

1. Tell me some thing about how do you discuss with the child about HIV/AIDS? Why?
2. How often the child does get counseling service about HIV/ AIDS? Why?

የስምምነት ፎርም |(ከጥናቱ ተሳታፊዎችጋር)

እንደምን ዋሉ፣ ስሜ__________ይባላል።የመጣሁት ከአዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ ት/ቤት ነው።ጥናት በማካሄድ ላይ እገኛለሁ።ጥናቱ ወላጆች/አሳዳጊዎች ህፃን ልጆቻቸው በኤች አይ ቪ መያዛቸውን ለህፃናቱ ለመንገር የሚገጥማቸው ፈተና ና ያላቸውን ልምድ ምን እንደሚመስል ማየት ነው።የጥናቱ አላማዎችም ወላጆች ወይም አሳዳጊዎች ልጆቻቸው ኤችአይ ቪ ፖዘቲቭ መሆናቸውን ግልፅ በማውጣት ላይ ያላቸውን ልምድ መፈተሸ፣ የልጆቻቸውን ጤና በምን መልኩ እንደሚጠብቁ ማየት እና ለልጆቻቸው ለመንገር/ላለመንር ምን እንዳነሳሳቸው ለይቶማውጣት ነው።በውይይታችን ላይ ለሚነሱ ጥያቄዎች ምላሻችሁ ለልጆቻችሁ ግልፅ በማውጣት ወይም ባለማውጣት ላይ የገጠመዎት ፈተና እና ልምድ ምን እንደሆነ መግለፅ ስለሆነ ምላሽዎ ትክክል ወይም ስህተት ነው አይባልም።

በቃለመጠይቁ ውስጥም አንዳንድ ለመንገር የሚያስቸግሩ ወይም ሚስጥራዊ የሆኑ ነገሮች ሊኖሩስለሚችሉ ከወዲሁ የምገልፅልዎ ነገር ቢኖር ምላሾ ምስጥራዊነታቸው እንደሚጠበቅ ነው።በጥናቱምላይ የርስዎን ማንነት የሚገልፅ እና የምትታወቁበት ነግር ምንም አይኖርም።የሚሰጡት ምላሽም ለዚህ ጥናት አላማ ብቻ የሚውል ነው።በተጨማሪም የጥናቱ ውጤት ቢታተም እናኳ በጥናቱ ላይ ተሳታፊየነበሩት አጠቃላይ መረጃ ብቻ ነዉ የሚወጣው።

በዚህ ጥናት ተሳታፊ የሚሆኑት ፍቃደኛ የሆኑ ሰዎች ብቻ ናቸው።ሆኖም ግን በጥናቱ ላይ ባለመሳተፍዎ የተነሳ በርስዎ ላይ ከማንኛውም ቦታ በሚያገኙት አገልግሎት ላይ የሚያመጣው ተፅኖ የለም። ቃለ መጠይቁንም ባስፈለገዎት ጊዜ ማቋረጥ ይችላሉ።

የሚሰጡት ምላሾች ተአማኒነት ያለው ቢሆን ጥናቱን የሚያጠናው ሰው ችግሩን በደንብ እንዲገነዘበው ይረዳዋል።ሥለዚህ ነፃ ሆነው የሚሰማዎትን ነገርና ያላችሁን አስተያየት ይንገሩኝ።

በምናደርገው ቃለምልልስም የሚያመልጠኝ ነገር እንዳይኖር የመቅረፀ ድምፅ እጠቀማለሁ። በመጨረሻም ይህ ጥናት ውጤታማ እንዲሆን የርስዎ ቀና ትብብር በጣም አስፈላጊ እና ወሳኝ መሆኑን እየገለፅኩ ይተባበሩኝ ዘንድ በትህትና እጠይቃለሁ።

በጥናቱ ለመሳተፍ ፍቃደኛ ነዎት?

አዎን

አይ

ሥለፍቃደኛነትዎ አመሰግናለሁ!

አዲስ አበባ ዩኒቨርሲቲ

የሶሻል ወርክ ት/ቤት

ከጥናቱ ተሳታፊዎች ጋር ለተደረገ የቃለመጠይቅ መምሪያ

1) የማህበራዊ ሁኔታ ጥናት

I.ወላጅ/አሳዳጊ

1.1 እድሜ ________

1.2 የት/ደረጃ

ያልተማረ/ች ________
ማንበብና መፃፍ የሚችል/የምትችል _
አንደኛ ደረጃ ያተናቀቀ/ች____
ሁለተኛ ደረጃ ያተናቀቀ/ች _
የኮሌጅ ዲፕሎማ __
የኮሌጅ ዲግሪ ___
ሌላ ካለ ይግለፁ__

1.3 የስራ ሁኔታ

የመንግስት መ/ቤት ተቀጣሪ _______
የግል ድርጅት ተቀጣሪ __________
የቤት እመቤት _____
ነጋዴ _______
ሌላ ካለ ይግለፁ ______

1.4 ሀይማኖት

ኦርቶዶክስ ______
ሙስሊም _______
ካቶሊክ _____
ፕሮቴስታንት_______
ሌላ ካለ ይግለፁ _______

1.5 የጋብቻ ሁኔታ

ያገባ ______
ያላገባ _____
በሞት የተለያዩ __________
የተፋታ_____

1.6 ከህፃኑ ጋር ያለዎት ግንኙነት

እናት ____
አባት ____
አሳዳጊ ___

II) የህፃኑ ሁኔታ

ፆታ ______
እድሜ______
የት/ደረጃ

1. የመግቢያ ጥያቄ

1.1. እስቲ ሥለ ቤተሰባዊና ማህበራዊ ህይወትዎ የንገሩኝ

1.2.በምትታመሙ ጊዜ በሽታዎን ለማስወገድ የሚደርጉት እርምጃ /የሚያሳዩት ባህሪ/ ምንድን ነው?

1.3.ስለ ኤች አይ ቪ ኤድስ ምንየሚያዉቁት ነገር አለ?

2.ግልፅ የማውጣት ልምድ

2.1 ልጅዎ በቫይረሱ መጠቃቱን ያወቁት እንዴት ነበር? በዚያን ጊዜ የነበረዎት
ስሜት እንዴት ይገልፁታል ?

2.2.ልጅዎ ከቫይረሱ ጋር አብሮእንደሚኖር ያውቃል? መቼ? ለምን?ከዚያስበኃላ ምን ተከሰተ?

2.3.ግልፅ ስለማውጣት ያለዎት አመለካከትና ስሜት ምንአይነት ነው?

2.4.ግልፅ የማውጣት ሂደቱ ላይ ማን አብርዎት ነበረ/እንዲኖር ይፈልጋሉ? ለምን?

2.5.ስለልጅዎ የኤች አይቪ ሁኔታ ማን ያውቃል? ለምን?

2.6.እስቲ ግልፅ ካወጡ በኃላና ከማውጣትዎ በፊት ከልጅዎጋር ያለዎት ግንኙነት ምን ይመስል
እንደነበር ይንገሩኝ

3. ማስታመም

3.1 ህፃኑ ህመሙን በተመለከተ ስለሚያነሣቸው ጥያቄዎች እስቲ ይንገሩኝ። ምን ብለውስ
ይመልሱለታል? ምንስ ይሰማዎታል?

3.2 ህፃኑ መድሀኒቱን በመውሰድ እና ሆስፒታል በመሄድ ላይ ያለው ተነሳሽነትን እንዴት
ያዩታል?

3.3 ህፃኑ ምንአይነት ባህሪ እና የማህበራዊ ግንኙት እንዳለው ይንገሩኝ

4) ግልፅበማውጣት ወይም ባለማውጣት ያለ ተነሳሽነት

4.1. ከህፃኑ ጋር በምን መልኩ ነው ስለ ኤች አይ ቪ እንደሚነጋገሩ ይንገሩኝ።ለምን?

4.2. ህፃኑ የምክር አገልግሎት አግኝቶ ያውቃል? ለምን ?

Annex II

Consent Form (Counselor Nurses)

Good after noon! My Name is _____ from Addis Ababa University graduate school of Social Work. I am doing research, the topic of the research is “Disclosing HIV Positive Status to Children: Challenges and Experiences of Mothers and/or Women Guardians from Zewditu Memorial Hospital.Therefore, objectives of the research are to explore experiences of mothers and/or women guardians toward disclosing HIV positive status of children, to assess the situations of mothers and/or women guardians on managing the illness of children and to find out the existing cue factors that motivate mothers and/or women guardians to disclose or not.

Your responses for the questions should base on the experiences that you have faced in your work with mothers and /or women guardians with HIV infected children. Therefore, there is no right or wrong answers. I would like to assure you ahead that your responses will kept confidential. On the report, there will no be any information that will identify you and your responses. Your responses will used for this research purpose only.

Yes

No

Name _________ Date ___________ Signature __________

Thank you, for your willingness!

Addis Ababa University

School of Social Work

Interview Guide for Counselor Nurses

Experience of Disclosure

1. Is there any significant variation between adult and child disclosure of HIV status? How do you describe it?
2. What is your point of view in disclosing HIV positive status the child? Why?
3. How do you express the mother's and /or women guardian's health seeking behavior?
4. How mothers and /or women guardians initiate to know about their child's health status? What was their reaction at that moment?
5. Whom do mothers and /or women guardians relay on to help to disclose the sero-positive status of their child? Why?
6. From your experience, for who mothers are willing to disclose their child's HIV positive status.

Illness Management

1. From your experience, what kind of questions children ask in relation to their illness? What kind of advise do you give them to respond?

2. How do you assess the children's interest in taking medication and visiting Hospital?

3 How do you help mothers and /or women guardians in managing change observed on the child in relation to his/her behavior and socialization?

Motives to disclose or not

1. How often mothers/women guardians or the child got counseling service? Why?

የስምምነት ፎርም II

እንደምን ዋሉ፣ ስሜ____________ይባላል።የመጣሁት ከአዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ ት/ቤት ነው።ጥናት በማካሄድ ላይ እገኛለሁ።ጥናቱ ወላጆች/አሳዳጊዎች ህፃን ልጆቻቸው በኤች አይ ቪ. መያዛቸውን ለህፃናቱ ለመንገር የሚገጥማቸው ፈተና ና ያላቸውን ልምድ ምን እንደሚመስል ማየት ነው።የጥናቱ አላማዎችም ወላጆች ወይም አሳዳጊዎች ልጆቻቸው ኤችአይ ቪ. ፖዘቲብ መሆናቸውን ግልፅ በማውጣት ላይ ያላቸውን ልምድ መፈተሽ፣ የልጆቻቸውን ጤና በምን መልኩ እንደሚጠብቁ ማየት እና ለልጆቻቸው ለመንገር/ላለመንር ምን እንዳነሳሳቸው ለይቶማውጣት ነው።በውይይታችን ላይ ለሚነሱ ጥያቄዎች ምላሻችሁ ለልጆቻችሁ ግልፅ በማውጣት ወይም ባለማውጣት ላይ የገጠመዎት ፈተና እና ልምድ ምን እንደሆነ መግለፅ ስለሆነ ምላሽዎ ትክክል ወይም ስህተት ነው አይባልም።

በውይይታችን ላይ ለሚነሱ ጥያቄዎች ምላሻችሁ በስራችሁ ላይ ሆናችሁ ወላጆች ለልጆቻችሁ ግልፅ በማውጣት ወይም ባለማውጣት ላይ የሚገጥማቸውን ፈተና ምን እንደሆነ መግለፅ ስለሆነ ምላሽዎ ትክክል ወይም ስህተት ነው አይባልም።

ከወዲሁ የምገልፅልዎ ነገር ቢኖር ምላሾ ምስጥራዊነታቸው እንደሚጠበቅ ነው።በጥናቱምላይ የርስዎን ማንነት የሚገልፅ እና የምትታወቁበት ነግር ምንም አይኖርም።የሚሰጡት ምላሽም ለዚህ ጥናት አላማ ብቻ የሚውል ነው።

በምናደርገው ቃለምልልስም የሚያመልጠኝ ነገር እንዳይኖር የመቅረፀ ድምፅ እጠቀማለሁ። በመጨረሻም ይህ ጥናት ውጤታማ እንዲሆን የርስዎ ቀና ትብብር በጣም አስፈላጊ እና ወሳኝ መሆኑን እየገለፅኩ ይተባበሩኝ ዘንድ በትህትና እጠይቃለሁ።

በጥናቱ ለመሳተፍ ፍቃደኛ ነዎት?

አዎን

አይ

ሥለፍቃደኛነትዎ አመሰግናለሁ!

አዲስ አበባ ዩኒቨርሲቲ

የሶሻል ወርክ ት/ቤት

የምክር አገልግሎት ከሚሰጡ ነርሶች ጋር ለተደረገ የቃለመጠይቅ መምሪያ

1.ግልፅ የማውጣት ልምድ

- ለህፃናትና ለአዋቂዎች ግልፅ ማውጣት ላይ የሰፋ ልዩነት አለ? ካለስ እንዴት ይገልፁታል?.
- እርሶ ህፃናት የኤች አይ ቪ. ሁኔታቸውን ማወቅ አለባቸው በሚለው ሀሳብ ላይ ያለዎት አመለካከት ምንድን ነው?ለምን?.
- ወላጆች/አሳዳጊዎች በሽታዎን ለማስወገድ የሚደርጉት እርምጃ /የሚያሳዩት ባህሪ/ ምን ይመስላል?
- ወላጆች /አሳዳጊዎች የልጆኣቸውን ኤች አይ ቪ. ሁኔታ በምንመላኩ ነው ሊያውቁ የሚችሉት ቢነግሩኝ፣በሰአቱ የሚያሳዩት ስሜት ምንነአይነት ነው?
- ወላጆች /አሳዳጊዎች ለልጆቻቸው ኤች አይ ቪ. ሁኔታን ግልፅለማውጣት በሚፈልጉጊዜ ማን አብራቸው እንዲሆን ይፈልጋሉ? ለምን?
- ወላጆች /አሳዳጊዎች የልጆኣቸውን ኤች አይ ቪ. ሁኔታ ለማን መንገር ይፈልጋሉ?

2.ማስታመም

- ካለዎት ልምድ የተነሳ ህፃናቶች ህመማቸውን በተመለከተ ስለሚያነሣቸው ጥያቄዎች ምን እንደሆኑ እስቲ ይንገሩኝ። እንንተስ ወላጆችን / አሳዳጊዎችን ምን ብለው እንዲመልሱ ታበረታታላችሁ?
- ህፃናቶች መድሀኒት በመውሰድ እና ሆስፒታል በመሄድ ላይ ያለው ተነሳሽነትን እንዴት ያዩታል?
- ልጆች ለሚያሳዩት የባህሪም ሆነየማህበራዊ ግንኙነት ለውጥ እናቶች/አሳዳጊዎች በማንመልኩ እንደሚያስተካክሉ ይመክራሉ?

3.ግልፅበማውጣት ወይም ባለማውጣት ያለ ተነሳሽነት

- ህፃንቶችና ወላጆች ወይም አሳዳጊዎች ለምን ያህል ጊዜ የምክር አገልግሎት ያገኛሉ?

Declaration

I, the under signed, declare that this thesis is my original work and has not been presented for a degree in any university, and that all sources of the materials used for the thesis have been duly acknowledged.

Name JEMILA ABDELLAH

Date Aug. 20- 09

Signature ____________________

This thesis has been submitted for examination by my approval as a university advisor.

Name of the advisor ____________________

Signature ____________________

Date of submission ____________________