# ADDIS ABABA UNIVERSITY
# SCHOOL OF GRADUATE STUDIES

## BEING A WOMAN AND LIVING WITH HIV/AIDS: SOCIO-CULTURAL AND ECONOMIC PROBLEMS AFFECTING WOMEN LIVING WITH HIV/AIDS IN ARADA SUB-CITY, ADDIS ABABA

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**MARCH 2007**

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**BY**
**NEBYU MEHARY**

**MARCH, 2007**

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| | |
|---|---|
| AACAHB | Addis Ababa City Administration Health Bureau |
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Anti-Retroviral Therapy |
| CCP | Community Communication Program |
| CSA | Central Statistics Authority |
| EDHS | Ethiopian Demographic and Health Survey |
| FGD | Focus Group Discussion |
| FGM | Female Genital Mutilation |
| HAPCO | HIV/AIDS Prevention and Control Office |
| HAPCSO | Hiwot HIV/AIDS Prevention, Care and Support Organization |
| HIV | Human Immunodeficiency Virus |
| HBCG | Home-based Care Giver |
| HTP | Harmful Traditional Practice |
| ICRW | International Center for Research on Women |
| MOH | Ministry of Health |
| NACP | National AIDS Control Program |
| NCHTP | National Committee on Harmful Traditional Practices |
| NGO | Non-governmental Organization |
| PCSA | Participatory Community Support Association |
| PLHA | People Living With HIV/AIDS |
| PMTCT | Prevention of Mother to Child Transmission |
| STI | Sexually Transmitted Infection |
| VAW | Violence against Women |
| VCT | Voluntary Counseling and Testing |
| UNAIDS | Joint United Nations Program of HIV/AIDS |
| UNRISD | United Nations Research Institute for Social Development |
| WHO | World Health Organization |
| WLHA | Women Living With HIV/AIDS |

## *Abstract*

*The study has focused on identifying the socio-cultural and economic challenges encountering women living with HIV/AIDS, coping strategies, their basic needs, their roles in the prevention efforts and factors that make women vulnerable to HIV infection. The target population of the study is mainly women living with HIV/AIDS. In-depth interviews, group discussions and a questionnaire are employed to collect data. The study has found that poverty, in association with other socio-cultural factors, is one of the major factors that increase women's vulnerability. The study has also shown that women living with HIV/AIDS face severe socio-cultural and economic problems. Stigma and discrimination are identified as the major challenges that WLWHA are facing.*

*The study has found that the participants employ a variety of strategies to cope with socio-cultural, economic and emotional challenges. A majority of the participants visit religious sites for Holy waters and they turn to religion and prayers. Disclosure of one's HIV status to support institutions and denial to neighbors and family members is also employed in order to cope up with socio-cultural and economic challenges. The study has also assessed the major needs of the participants. Some of the major needs are financial assistance, employment opportunities, access to healthcare services, housing, food aid, support for their children, social acceptance, and emotional support.*

*The study has found that women living with HIV/AIDS have been playing significant roles in the prevention and control efforts. Their roles range from protecting others by implementing precautions to a wide range of participation in awareness creation programs. However, there are still obstacles that have deterred the roles. These obstacles include stigma and discrimination, pressures from husbands or sexual partners, household burdens, health problems, and limited knowledge on how to participate in the prevention efforts.*

# 1. INRODUCTION

## 1.1 Background

Acquired Immune Deficiency Syndrome (AIDS) is caused by Human Immunodeficiency Virus (HIV). The virus was first identified in 1981 in the USA among young homosexual men. In the early 1980s, AIDS cases were found among injected drug users, some blood transfusion recipients, a few new born infants (Essex and Souleyman, 2002). It then spread allover the world and has become one of the most deadly diseases causing severe social, economic and demographic crisis.

HIV/AIDS is not evenly distributed as far as infection rates are concerned. That is, the highest proportion of people living with HIV/AIDS is found in Africa in general and in sub-Saharan Africa in particular. UNAIDS report in 2006 confirms that among 38.6 million (33.4-46.0 million) people infected with the virus in the world, the majority live in sub-Saharan Africa. Thus, the region has remained with the largest burdens of the AIDS epidemic (UNAIDS, 2006).

HIV started to spread in Ethiopia in the early 1980's. According to a report from the Epidemiology and AIDS Department of Ministry of Health (MOH, 1998), the first evidence for HIV infection in Ethiopia was found in 1984. In the 1990's, the spread increased alarmingly particularly in urban areas and in 1997, it was estimated that adult prevalence ratio reached 7.4%. The spread continued and in 2003, the prevalence ratio reached 12.0% in urban areas and 8.2% in rural areas (MOH, 2004). In the year 2005, the number of PLHA reached 1.32 million at national level (MOH, 2006). The same report states that there were 134, 450 AIDS deaths, 137,500 new AIDS cases, 128,900 new HIV infections and 744,100 AIDS orphans in 2005. As a result of these facts, Ethiopia has become one of the world's most affected countries.

The Ethiopian government responded to the epidemic by forging multi-sectoral partnership with various stakeholders and by enacting policies and strategies of minimizing the spread of the virus (HAPCO, 2003). In 1985, the national AIDS taskforce was established focusing on prevention of the spread of HIV/AIDS and its impacts. The National AIDS Control Program (NACP) was established in 1987 and HIV surveillance began in 1998 (MOH, 2006). In 1998, a national policy on HIV/AIDS was enacted (CAFOD, 2003). Following this, a five year (2000-2004) strategic framework was produced. The major areas of intervention proposed by the policy include behavioral change communication (BCC), condom promotion and distribution, blood safety, management of sexually transmitted infections (STIs), voluntary counseling and testing (VCT), prevention of mother to child transmission (PMCT), care and support to PLHA, universal precautions, legislation and human rights, and surveillance research (HAPCO, 2003).

However, though the policies as well as strategies have to some extent recognized the need of giving special focus for women in the interventions, little changes have been achieved. According to the International Center for Research on Women (ICRW) (sited in Khaturi, 2003), most AIDS prevention efforts failed for two reasons. One is that the efforts mostly target commercial sex workers and to lesser extent adolescent girls who attend school. Prevention programs do not reach the majority of women with a different socio-economic background. Second, the interventions have little concern to the broader social, economic and cultural context in which high risk occurs. There is also lack of reliable data on women's sexual life and the way in which socio-economic and cultural factors determine their sexual experiences (Khaturi, 2003).

HIV/AIDS has a different implication for men and women. That is, women's vulnerability to HIV is higher than that of men's for various reasons. Available sources indicate that in the early ages of the pandemic, more men were infected than women. However, the situation is reversed currently. UNAIDS report in 2005 indicates that increasing number of women and young girls were being infected particularly in sub-Saharan Africa. The report indicates that, young girls between the ages 15 and 24 are at least three times more likely to be HIV positive than young men of the same age group. This can also be true in Ethiopia where the rate of infection of women outnumbers that of men's as of 2003 (MOH, 2004).

The major factors that increase women's vulnerability are identified to be physiological (biological), socio-cultural, and economic. Biologically, HIV is generally more easily transmitted from men to women than vice versa (WHO and UNAIDS, 2003). In most parts of Ethiopia various harmful traditional practices (such as female genital mutilation, early marriage, abduction, polygamy, wife inheritance etc.) are common. Such practices have increased the risks of HIV transmission among women and young girls (Fekerte, 2004). In addition, poverty, gender differences in knowledge, sexual behavior, risk perception, and access to resources have their own roles to play in increasing women's vulnerability (Balyagati & Schapink, 1997).

The increased vulnerability of women to the virus has in turn produced a relatively large number of women living with HIV/AIDS. In a society where women hold lower social and economic status, it could be more difficult to live with the virus and its impacts. Thus, there is a need of understanding and solving the problems of women including those who live with the virus. Therefore, this study will be undertaken in order to identify the socio-cultural and economic problems that are affecting

women living with the virus. This in turn will have significant importance in the prevention and control efforts.

## 1.2 Statement of the Problem

It is true that HIV/AIDS affects men and women differently as far as the Ethiopian case is concerned. And, women constitute the majority of PLHA in Ethiopia. A recent report from the Ministry of Health (MOH, 2006) shows that, HIV prevalence is 11.9 percent for females and 9.1 percent for males in urban areas. Thus, considering the lower socio-economic status women hold in the society, women with the virus face countless problems.

Researches in Sub-Saharan African countries have shown that women living with HIV/AIDS face relatively more barriers than men in seeking and accessing health care services. They are more likely to be rejected, to be expelled out of home and to be denied treatment, care and basic rights (Johnson, 2002). Literature shows that married women more often are tested for HIV/AIDS when they are pregnant to prevent mother to child transmission. If they are found to be HIV positive, they are more likely to be considered as vectors that brought the virus to the family though men also have a possibility of bringing it to the family. As a result, women with the virus face rejection, stigma and discrimination, and violence more severely than men (Johnson, 2002). Moreover, women and young girls have been carrying the burdens of providing care and support to HIV patients.

The problems are more severe among the widowed. Due to gender inequality in access to and control over resources, women in many societies of Ethiopia are dependent on men's income. Thus,

breadwinners in many societies are husbands and death of the husbands would mean women suffer with their children. Thus, women living with the virus are carrying triple burdens; being women, infected with the virus and carrying the severe impacts of the virus.

It is clear that HIV/AIDS has become a major issue in Ethiopia. Yet, much attention has not been given to its differential effect on women including the problems of women living with the HIV/AIDS. Thus, it is important to understand and consider the problems that women living with HIV/AIDS are facing. To this effect, the following are the research questions.

1. What are the socio-cultural and economic challenges that women living with HIV/AIDS face in Arada sub-city, Addis Ababa?
2. What strategies do women living with HIV/AIDS use to cope with socio-cultural and economic challenges?
3. What are the critical needs of women living with HIV/AIDS?
4. What roles could women living with HIV/AIDS play in the prevention and control efforts?

## 1.3 Objectives of the Study

### *General Objective*

The over all objective of the research is to understand the problems that are affecting women living with HIV/AIDS in the area under study and to find out how these problems affect women's day to day lives. In addition, the study is aimed towards giving voice for poor and vulnerable women whose problems are less considered.

### *Specific Objectives*

The following are the specific objectives of the research.

a) to identify the socio-cultural and economic problems that are affecting women living with HIV/AIDS;
b) to explore how women living with HIV/AIDS strive to cope with the virus and its impacts in their day to day lives;
c) to identify the critical needs of women living with HIV/AIDS;
d) to assess the roles women living with HIV/AIDS could play in the effort to reduce the spread of the epidemic;
e) to identify the factors that contribute to women's vulnerability to HIV infection.

**1.4 Significance of the Study**

Nowadays HIV/AIDS has become the most devastating epidemic in the country. Various efforts have been made to control the spread of the virus at all levels. But these efforts have little contributions. This is because most of the efforts to fight the epidemic were concentrating on awareness creation about HIV and AIDS. The problems of people living with HIV/AIDS and the roles they can play in the prevention and control efforts have not been given much emphasis in the works.

Also, there has been little effort in bringing behavioral changes in the general public. This in turn has resulted from the mistreatment of people with HIV/AIDS at home, at work places and generally in the society. Such activities have their own roles to play in increasing the rate of transmission. Women in particular are the primary victims as they hold high infection rates and lower socio-economic status. This research therefore has the significance of contributing in identifying the problems that women living with HIV/AIDS are facing.

Thus, in addition to its academic significance, this study will provide possibilities to give information to different bodies in their attempts to

fight the disease. It assists in identifying the socio-cultural and economic aspects of the disease, as they are believed to facilitate the further aggravation of the disease. Moreover, the results of the study may help as a point of departure for other researchers who want to undertake studies in the area.

### 1.5 Delimitations of the Study

This study is undertaken among specific target groups and in a specific area. It deals only with women living with HIV/AIDS above 15 years old in Arada sub-city, Addis Ababa. It does not have accounts of men's experiences with HIV/AIDS as this is not been the scope of the study. Moreover, it deals only with those women who are poor and vulnerable as they are the primary victims of the problem. It may not represent women who live in rural areas with a different socio-cultural and economic setting. More importantly, it focuses on selected aspects of the problems.

### 1. 6 Limitation of the Study

This study is undertaken within a specific cost and time. The researcher employed both qualitative and quantitative tools of data collection which has requested much more cost. Moreover the researcher is required to consider ethical rules and reciprocity which need indirect expenses. The nature of the target groups required time to contact participants, to create rapport and get an insider position among them. A small sample size was administered for the quantitative study as it is very difficult to get a large number of participants for various reasons. Moreover, the researcher could not apply sampling frame for selection of the respondents in the quantitative study for various reasons; inaccessibility of participants (WLWHA), limited rate of disclosure among WLHA, and lack of willingness to participate in studies among many of the target groups.

# 2. REVIEW OF RELATED LITERATURE

## 2.1 The Spread of HIV/AIDS in Ethiopia

Ethiopia has an estimated population of 77 million at the end of 2005. About 43 percent of the population is under the age of 15 years. Moreover, 84% of the country's population lives in rural areas (MOH, 2006). The county's economy is characterized by slow growth and poor performance of the agricultural sector which holds the majority of labor. The recent history of the country, particularly the last three decades, is characterized by recurrent drought, famine, internal and external conflicts and natural disasters. In the last two and half decades, HIV epidemic is added making the situations worse.

HIV/AIDS first appeared in the early 1980's in Ethiopia. According to sources, the first evidence of HIV infection was discovered in 1984 (MOH, 1998). Since then, the epidemic spread steadily in the country through heterosexual sex which is the major mode of transmission of HIV in Ethiopia. In addition, there are harmful traditional practices that contribute significantly in spreading the virus. It has been indicated that the virus first spread primarily through commercial sex workers, soldiers and truck drivers in the major towns (MOH, 2004). Gradually the infection spread to the general public all over the country.

The rate of transmission of the virus was slower at the beginning (MOH, 1998). The infection rate was also higher among men than women. But later, when the infection rate accelerated through the 1990's, more women became infected. For example, in 1990, the prevalence ratio reached 1.5 percent for men and 1.7 percent for women. The difference increased in the late 1990's and in 2000 it became 3.4 percent for men

and 4.4 percent for women (MOH, 2004). The same report states the condition of women in relation to the spread of disease as follows.

> Two large population groups are carrying the brunt of the disease_ rural Ethiopia and women. Because of significant gender inequalities (lower socio-economic standing); women are increasingly bearing the brunt of the disease and its impact. This in turn results in high stigma, discrimination and poorer access to health care services. Moreover in most Ethiopian societies, it is the responsibility of women and girls to care for the sick at the family level (p.22).

In general, the trend of the epidemic from 1995 till 2003 suggests a continuing gradual rise in national prevalence. That is 3.2% for 1995; 4.1% for 2001; 4.2% for 2002, and 4.4% for 2003. It is also characterized by high urban prevalence than rural. In rural Ethiopia, a very gradual and steady rise has been observed from 1990 on with women holding higher infection rates. Moreover, women are infected at much earlier ages (15-19) than men (20-24). Also, younger females who are living with HIV/AIDS outnumber males, while more males are observed in older groups (30 + years) (MOH, 2006). The estimated urban prevalence in 2005 was 11.9 percent for females and 9.1 percent for males. In the same year, the national prevalence was 3.5 percent (3% for men and 4% for women). It has shown a decline from formerly projected estimations (MOH, 2006).

The virus has been exerting impacts on the different sectors in the country. Demographically, it has caused reduction in population. In 2005, it is estimated that 1.32 million people were living with the virus (MOH, 2006). The epidemic has greatly affected the human resource development of the country due to high rate of mortality and morbidity of adults in their productive ages. In 2005 alone it is estimated that there were 134,450 AIDS deaths among which women accounted for 54.5% of all deaths. As a result, AIDS has reduced the life expectancy of

Ethiopians by 5 years (MOH, 2006). The mortality of adults in turn has produced large number of orphans. For instance in the year 2005 alone, there were 744, 000 AIDS orphans (MOH, 2006). In a country like Ethiopia where social services are limited, orphans are more often left to their grand parents who have either low income or unable to support themselves.

The educational sector is one area that is greatly affected by the epidemic. A research conducted by the Ministry of Education (sited in MOH, 2004) in the year 2003 indicates that there was 5 percent increase in death of teachers from HIV/AIDS and other related diseases. In addition, school dropout rates increased from 1996/97 to 2000/2001 possibly due to sickness and death of parents. It is thus believed that these negative effects influence the quality of education directly or indirectly.

***HIV/AIDS in Addis Ababa***

Compared to rural areas, urban centers carry large proportion of infection rates as well as people infected with HIV in Ethiopia. As stated before, the virus was primarily distributed in urban areas through commercial sex workers, truck drivers and soldiers. Report from the Ministry of Health in 2006 indicates that in the year 2005, urban areas hold 686,000 people living with HIV/AIDS out of 1.32 million. Urban areas account for only 16% of the total population of the country while holding over 52 percent of PLWHA. In 2005, HIV prevalence is estimated to reach 9.5% in urban centers and 2.2% in rural areas (MOH, 2006).

Addis Ababa is one of the urban centers that are hardest hit by HIV. The number of PLHA in Addis Ababa is estimated to reach 207,270 in 2005 (MOH, 2006). It is estimated that there were 241,000 and 246,000 PLHA

in 2003 and 2004 respectively in Addis Ababa. New HIV infections in Addis Ababa account for about 20,000 in 2003 and 29,000 in 2004. In 2003 and 2004, there were approximately 9,300 and 9,600 HIV positive pregnant women respectively in Addis Ababa. There were also 9,300 children living with HIV in 2003. In 2004, there were about 59,000 maternal AIDS orphans 52,000 paternal AIDS orphans and 26,000 dual orphans (MOH, 2004).

## 2.2 Factors Contributing to Women's Vulnerability

According to Whiteside et al. (2002:28), vulnerability describes "those features a society, a social or economic institution or process that makes it more or less likely that excess morbidity and mortality associated with disease will have negative impacts". Compared to men, women are by far more exposed to the virus for various reasons; physiological (biological), socio- cultural and economic. Tina Johnson (2002:7) elaborates the gender differences between men and women to create variations in the rates of vulnerability as follows:

> An examination of the realities of women's and men's lives reveals variations in personal, physical, social and economic powers and capacities. These differences are expressed at many levels of human activities and result in differential rates of risk, infection patterns, access to health knowledge and protection…

Currently, sources indicate that more women than men are infected as well as died of the virus. UNAIDS report (2005) urges the need to give special attention for the rights and status of women and young girls in order to halt the fast spreading of the virus. The factors that contribute to women's vulnerability are explained as follows.

### 2.2.1 Physiological (biological) Factors

Compared to men, women are more likely to contract the virus during any exposure of sexual intercourse. This is because the female reproductive organ has larger surface area compared to men. Moreover, the semen has high concentration of HIV than the female viginal secretion and it can stay in the female reproductive body for hours after sexual intercourse. Thus, during sexual intercourse, the females have higher risk of contracting the virus, as they are receivers of the male semen (Goldstine, 1997; Fekerte, 2004; Khaturi, 2003). This could be a major reason for the increase in the risk of infection of women as heterosexual sex is the primary mode of transmission in Ethiopia. In addition to this, women are asymptomatic to other sexually transmitted infections. This puts women at high risk of contracting the virus. This is because, women could stay without medical treatment being unaware of the infection and the virus could easily enter in to the women's body through invisible sores (Goldstine, 1997; Johnson, 2002; Khaturi, 2003, Fekerte, 2004). Women are less likely than men to seek healthcare services for sexually transmitted infections (STIs) for two reasons. One is that they are more likely to be socially stigmatized in their communities and within healthcare settings. Second, they many not recognize that they have STIs and they are often asymptomatic for many STIs (Long and Messersmith, 1998).

### 2.2.2 Socio- cultural Factors

Socio-cultural factors are the major reasons for increasing women's vulnerability to HIV. The lower status given to women in society has complicated the efforts to prevent and control the epidemic. Ethiopian society is traditional instituting harmful traditional practices that enable the transmission of the virus. Patriarchal outlooks that place women at the bottom of societal strata in social, economic and political lives are

deep rooted in Ethiopian society. They have contributed to the lower position of women. Some of the socio-cultural factors that increase women's vulnerability to the epidemic are discussed as follows.

***Early Marriage and Virginity***

Early marriage is a common practice in Ethiopia particularly in rural areas. The Ethiopian Demographic and Health Survey (2000) confirm that marriage as well as child bearing starts early in most parts of Ethiopia. In Ethiopia, about 55 percent of women are married before reaching puberty (Abebech, 2003). Even in Addis Ababa, 10 percent of currently married women are early married. Girls as young as 10 years old are married to older men for various reasons. Parents prefer to engage their daughters into marriage for fear of unwanted pregnancy and loss of virginity before marriage that are considered as shameful in society. In some situations parents prefer early marriage due to poverty.

Early marriage can increase the risk of HIV infection for young girls. In addition, it has the consequence of causing psychological trauma and spoiling girls' career. When girls are married to older men, they can be vulnerable to HIV infection because their husbands are expected to have had a number of sexual partners before the marriage (Population Reports, 2001 cited in Wuleta, 2002). This has serious implications for the sexual and reproductive health of the young women. The reproductive organ of young girls is not well developed to endure sexual relations with older men. More over, the genital tract of young girls is less efficient as a barrier to HIV than the matured genital tract of older women (Goldstine, 1997; Abebech, 2003; Khaturi, 2003).

Also, in many societies, high value is given to virginity and girls are expected to protect it and to stay ignorant about sexual matters. The

high social value placed on virginity in unmarried girls may pressure parents and the community to ensure that young women are kept ignorant about sexual matters. Female ignorance of sexual matters is often viewed as a sign of purity and innocence. In many cultures, being knowledgeable about sex would lead to negative views for young women.

The social pressure on young girls to remain virgin can contribute in a number of ways to the risks of STIs and HIV. Studies have shown that in some contexts, young women may engage in risky sexual practices (such as anal sex) as a means of protecting their virginity (Rivers and Aggleton, ND). Also young girls are at high risk of infection because men think that virgin girls are less probable to be infected in the past and hence will be discouraged to use condoms. In such contexts, girls are possibly at high risk of infection assuming that men have had sexual relations with a number of partners before. The need to have sexual intercourse with virgin girls among older men further entrenches gender inequalities (Khaturi, 2003).

***Polygamy***

Polygamy is another institution that increases women's vulnerability to the virus. In many cultures, men have the freedom to be sexually active. Such cultures enable men to have multiple partners as well as greater decision-making power regarding sexual and reproductive matters. Women on the other hand are expected to stay innocent to the extent that they do not question their partners' behaviors. This puts them at high risk of contracting HIV (Mgalla et al., 1997).

According to the Ethiopian Demographic and Health Survey (2000), 16% of married women in Ethiopia were in a polygamous relationship. In a polygamous society, HIV can be spread to many women easily. In some

cultures of Ethiopia, there is a tradition of “wife inheritance”; a tradition in which a wife is married to her brother-in-law upon the death of her husband. There is also a tradition in which wives have sexual relations with their brother-in-laws (Wuleta, 2002). If either of the partners is infected, the other will be at risk.

***Infertility***

In most societies of Ethiopia, children are seen as economic assets and high value is placed on parenthood. In most African countries, mothers’ status is weighed in terms of the number of children they have (Mgalla et al., 1997). Thus, women may have sexual relationships with a number of partners in an effort to get pregnant. Also, if women are infertile, there is high probability of marital breakdown among couples. In addition to this, the high value attributed to having large number of children discourage women from using family planning, including condom use. Furthermore, in attempt to have large number of children, men often marry young women (Wuleta, 2002).

***Violence against Women***

Many forms of violence against women such as rape, abduction, female genital mutilation and others are commonly practiced in many societies of Ethiopian. Women do not have the freedom to control their sexuality and many of them are forced to have sexual intercourse against their wills. The risk of HIV transmission is high under forced sex because condoms are not usually used. Violence also leads to bleeding and wounds which make the passage of the virus more likely (Khaturi, 2003).

Marriage by abduction is another violence against women that is commonly practiced in regional states like Southern Nations,

Nationalities and Peoples, Oromia and Benishangul-Gumuz. The occurrence of marriage by abduction at national level was 69 percent in 1998 (Abebech, 2003). Abduction may create a high possibility of HIV infection. Moreover pregnancy may occur resulting from the infection of the infant through mother to child transmission of the virus.

Circumcision of girls is also categorized under violence. It is practiced throughout the regional states of Ethiopia. According to the Ethiopian Demographic and Health Survey (2005), 75 percent of Ethiopian women are circumcised. In addition to its role in controlling women's sexuality and decreasing their sexual pleasure, circumcision facilitates HIV transmission. This is because of two reasons. First, circumcision in many cases is carried out using unsterialized equipments (Fekerte, 2004; Wuleta, 2002). Second, for circumcised women, there is high possibility of vaginal bleeding during sexual intercourse. On the other hand male circumcision minimizes the risk of AIDS transmission. Circumcised men are less vulnerable of HIV infection through sexual intercourse than uncircumcised men. In some communities, male circumcision is not a common practice (Mgalla et al., 1997). However, there is still risk of HIV infection within male circumcision if it is carried out with unsterialized equipments.

***Level of Awareness***

Women and men may not have equal access to information. Men have better exposure to information from discussions and different media sources as they mostly spend their times in the public sphere. Women on the other hand spend most of their time performing domestic responsibilities. As a result, the level of awareness about HIV/AIDS is not the same among men and women. Women by far are less likely to have more detailed knowledge about HIV/AIDS (Mgalla et al., 1997;

MOH, 2004). According to the Ethiopian Demographic and Health Survey (2005), women have less knowledge of the existence of the virus compared to men. The report shows that 89.9 percent of women aged 15-49 years have heard of HIV/AIDS compared to 96.6 percent of men between ages 15-59. The report has put that 81.2 percent of women compared to 93.3 percent of men believe that there is a way to avoid HIV/AIDS.

Men and women also have differences in attitudes, risk perceptions (concerning AIDS) and sexual behaviors. Risk perception is very important for controlling oneself from risky relationships. However, studies show that more men than women feel that they personally are at risk of AIDS (Balyagti and Shapink, 1997). Moreover, women are expected to be ignorant about sexual matters as a sign of purity. Such consideration prevents young girls from seeking information on sexual health including HIV/AIDS and discussing sex openly with their partners (Khaturi, 2003).

***Gender Differences in Decision Making on Sexuality***

Traditional views on the roles of men and women identify men as decision makers on issues related to sexuality. This has made women unable to refuse unwanted and unprotected sexual intercourse (Essex and Souleyman, 2002). Men are traditionally identified as initiators of sex where as women as passive participants. Sexually active young women do not discuss sex openly with their own partners. This has made them to feel that sex is something that happens to them. In addition, girls are commonly socialized to be submissive to men and are often pressured by boys to have sex as a proof of love and obedience. Young men in turn are encouraged to seek sexual experience. In some cultures, they are encouraged to use their adolescent years to experience sex. They

are also expected to be more knowledgeable, often as an indication of their sexual experience.
(From: http://www.undp.org/hiv/publications/gender/adolesce.htm)

Sex thus has continued to be defined in terms of male desire (Welhemina, ND). In many societies, women have no legal right to refuse sex to their husbands. For instance, marital rape has not still been prohibited by the law in Ethiopia. Many women do not question safer sex for fear of violence and rejection from their husbands. Thus, even if women have basic understanding of HIV and AIDS, rarely do they have the power to ensure that condoms are used (Khaturi, 2003, Welhemina, ND, Mgalla et al., 1997). Many women face the threat of physical violence if they are not sufficiently responsive to their partners' sexual desires. It is often the poorest women who have the fewest choices, run the most frequent risks and are more likely to become infected.

### 2.2.3 Economic Factors

In the Ethiopian context, men and women do not have equal economic opportunities. Women are by far poor and have limited access to resources and are dependant on men's support. Women's poverty and economic dependence makes it difficult to remove themselves away from relationships that increase the risk of infection of HIV/AIDS.

Poverty is the determining condition for risk of infection of HIV. There is strong relationship between HIV and poverty as most people with HIV/AIDS are the poor. The fact that sub-Saharan Africa holds the highest proportion of PLHA well establishes this truth. Poverty is seen as a key factor leading to behaviors that expose people to the risk of HIV infection. As women account for the majority of the poor, they are highly susceptible to the virus. Poor women lack control over of the

circumstances in which intercourse occurs. Those women with high level of income have better opportunity to cease themselves from engaging in risky relationships. Poor women who have no means of income rather than depending on their husbands' income could not dare to question their husbands' sexual behaviors (Collins and Rau, 2000). In Ethiopia for instance most married women who are at risk of infection of the virus through their husbands would not quit the marriage. This is because they perceive that the economic consequences of the risky relationship are far more serious than the health risk of staying (Wuleta, 2002). This may increase the frequency of intercourse and lose the age at which sexual activity begins.

Poverty increases the biological vulnerability of women to HIV infection. Malnutrition for instance inhibits the production of mucus and slows down the healing process of lesions which could make the entry of the virus to the woman's body more likely (Khaturi, 2003; Collins and Rau, 2000). Poverty also leads to the lack of access to acceptable health services. A poor woman is the least likely to access proper medical attention. Poor health services may allow the usage of unsterialized equipments by then increasing the risk of HIV infection (Siegal and Burke, 1997).

The economic determinants of HIV risk behaviors are strongly reflected in sex work. For many, sex work is a survival strategy. Sex workers are impoverished and are struggling for day to day survival for themselves and their families. For them, poverty is a compelling reason to accept clients who refuse to use condom. Thus, they are less likely to take the risks of HIV seriously. As a result, they are highly vulnerable to HIV infection **(**Collins and Rau, 2000; Wilkinson, 1997).

## 2.3 People Living with HIV/AIDS: Challenges, Needs, and Coping Strategies

### 2.3.1 The Challenges of Stigma and Discrimination

People living with HIV/AIDS are reported to face stigma from family members, co-workers, neighbors, care-givers, health workers and generally from the society. UNAIDS report (2006) indicates that stigma and discrimination against PLHA has remained persistent in many countries. Stigma around HIV and AIDS persist because "it is deeply enmeshed with social and personal views, fears, beliefs and taboos around sex and death" (Nyblade et al., 2003:15). People living with the virus also isolate themselves from different activities for fear of stigma. They have a feeling of shame and they blame themselves for contracting the virus.

***Causes of Stigma***

Studies have shown that lack of in-depth knowledge about HIV and AIDS, fear of death from AIDS, the way HIV is transmitted and absence of cure for AIDS are the major causes of stigma. Many people do not have a detail understanding of the symptoms of AIDS as well as ways of transmission of HIV. For instance, being underweight can result from suspension of HIV followed by stigma. Moreover people who have contracted opportunistic infections (TB and severe diarrhea for instance) are labeled as HIV positive and thus are stigmatized (Nyblade et al., 2003). Lack of sufficient knowledge has made people assume that HIV can be transmitted through physical contact. This has resulted from physical isolation with not only PLHA, but also people and equipments connected to PLHA (Yonas et al., 2004). Moreover, death from AIDS is seen as terrible and certain. Thus, lack of sufficient knowledge with the

fear people have developed about AIDS has made them avoid any contact with PLHA (Chapman, 2000).

The fact that HIV is transmitted through sexual intercourse has given HIV/AIDS a separate status from other diseases (Nyblade et al., 2003). PLHA have been considered to contract HIV through their promiscuous behaviors as sexual intercourse is the main mode of transmission. The absence of any cure for HIV has made it to be considered as a punishment from God. Thus, PLWHA are blamed and stigmatized for being "sinners" and for violating the norms of sexuality. This is particularly true in Ethiopia.

***PLHA's Experiences of Stigma***

Research findings indicate that PLWHA's experiences of stigma are similar across countries. However, the experiences vary according to socio-economic status, age, and gender. They are determined by the social context and the way PLHA are represented in specific contexts (Chapman, 2000; Nyblade et al., 2003; Yonas et al., 2004). In some situations, compared to the rich, the poor are less blamed as people realize that lower economic opportunities forced them to have risky relationships. But the rich are blamed as there is a belief that their wealth pushed them to infidelity. In other situations, unlike the poor, the rich face limited stigma because they can hide their positive status either because they have the capacity to pay for non-stigmatizing care or they change their residences to new places where their status is not known. The poor, however, are forced to disclose their HIV status in order to access services and benefits. This in turn makes them more vulnerable to stigma (Nybalde et al., 2003).

The experience of stigma among PLHA varies according to ages. Research findings confirm that the youth face stigma more severely than other age groups. This is because they are blamed for being attracted to material goods and for breaking sexual norms. They are also blamed for breaking community's traditions (Hailom, 2003; Nybalde et al., 2003). To this effect, they are highly stigmatized than other age groups.

Stigma experiences also differ across gender. Women (particularly sex workers and single women) are blamed for spreading the virus. In this case, they are highly stigmatized. In other situations, women are considered to be infected because either they are unable to protect themselves against risky relationships or due to poverty. In such cases they are less blamed (Nyblade et al., 2003). However, although men could bring HIV to a family or a community, unequal gender relations make women more likely to be blamed and then stigmatized.

Women are also more likely to face multiple stigma than men. Multiple stigma means that HIV stigma is added to pre-existing stigmas. Sex workers and infertile women for instance face multiple stigma. In addition to women, the poor, the youth and homo-sexuals face the challenges of multiple stigma (Chapman, 2000, Nybalde et al., 2003). This is because, in many societies, these groups face stigma even if they are not HIV positive. Thus, the experience of stigma among PLHA varies according to existing situations and perceptions of the society. Nybalde et al. (2003:28) wrote:

> The extent to which people with HIV and AIDS are stigmatized and discriminated against depends on 'who' they are (for instance they are men, women, sex workers, youth, rich, poor), 'where they are', (for instance, at home, in the health center, in church), and 'why' they are infected (whether they are assumed for their infections).

***Forms of Stigma***

According to Nyblade et al. (2003) the experiences have three broad forms; stigma against PLHA, internalized stigma (PLHA isolate themselves from the society) and stigma against those persons related to PLHA (such as children, family, care givers and health workers called secondary stigma). Stigma towards PLHA is manifested in differential treatment (physical and social exclusion from the family or community), gossip, loss of identity and role, and loss of access to resources and livelihoods. Physical exclusion is manifested in separating sleeping quarters, eating utensils and bed linings, and prohibiting PLHA from participating in house work. Social exclusion is manifested in reduction of daily social interaction with family and neighbors, and exclusion from family and community events.

PLHA in many countries are not seen as productive members of society. They lose power, respect and the right to make decisions. Moreover, they are expected to disclose their HIV status and to teach the society. Those who do not fulfill this have been viewed as selfish and irresponsible. However, PLHA, once their HIV positive status is disclosed, are more likely to face lose of employment, business and customers (Nyblade et al., 2003).

PLHA develop internal stigma because they internalize guilt and self blame for being HIV positive and accept their “inferior status” in society. Then they lose hope, and, being affected by stigma, they isolate themselves from social interactions and abandon life plans.

Stigma inflicts a wide range of impacts on the social, emotional and economic status of those who live with the virus. It has also its own roles to play in aggravating the further spreading of the epidemic. Stigma

influences public disclosure of one's HIV-positive status. It discourages people from visiting VCT centers. Stigma has also served as a barrier to introducing ART. (From: http://www.ackhcwep.org).

### 2.3.2 Needs of People Living with HIV/AIDS in Addis Ababa

A study conducted by Family Health International (FHI) categorized the needs of PLHA in to four: emotional and psychological, physical, socio-economic and health care (FHI, 2002). Among these, the most prominent needs of PLHA are identified to be emotional and psychological. PLHA have strong desires for social acceptance, sympathy and the concern of others. The study has shown that physical needs (nutrition, clothing and shelter) are the second major needs of PLHA. Due to poverty and low level of income, PLHA could not cover the expenses for nutrition. Moreover they are required to get better diet to cope up with the impacts of the virus. PLHA also need housing services as they experience stigma from private house renters. The other major need of PLHA is healthcare services. They also need medical support including professional counseling and psychological support to better withstand emotional problems that come with the virus. They also need home- based treatment and nursing services (FHI, 2002).

### 2.3.3 Coping Strategies

Coping strategies refer to the behavioral and psychological efforts that people use to tolerate or reduce stressful events (Lewis and Brown, 2002). PLHA may have to cope with loss of employment, rejection, impoverishment and the prospect of certain death. They are also subjected to ongoing stress. Thus, they employ different strategies to cope with these challenges. (MacArthur and John, 2003).

Available literature indicates that, PLHA employ varieties of coping strategies that change overtime, according to contexts. One is disclosing their positive status to get support form institutions, counseling centers, friends, family members etc. In other situations, PLHA hide their positive status in an effort to cope against stigma. PLHA also try to cope against stigma by moving to new places where their positive status is not known. This works for those PLHA who have better economic status. Some others try to cope against stigma directly by participating in prevention programs by then demonstrating that they have roles to play in society. Many others turn to religion and prayers. Also PLHA may employ different strategies at the same time. For instance, PLHA may disclose their status to support institutions and may hide to members of families and neighbors (Nyblade et al., 2003).

Research findings conducted in other countries among female adolescents with HIV/AIDS indicate that adolescent women with HIV employ different strategies of coping. Some of the major ones are, listening to music, thinking about good things, sleeping, eating, watching television, day dreaming and praying (Lewis and Brown, 2002).

### 2.4 Feminist Approach towards HIV and AIDS: Theoretical Context

HIV/AIDS is a major topic for feminist inquiry and theorizing for various reasons. According to Long and Messersmith (1998), HIV/AIDS addresses a critical feminist concern as it involves women's control over their own bodies. Moreover, HIVAIDS intersects with socio-economic and political disparities among classes, ethic groups, rural-urban residents, and men and women which are the hearts of feminist theory and analysis. Gender specially intersects with race, class, and sexuality that make the issue of HIV/AIDS a feminist concern (Goldstein, 1997). Moreover, gender inequality plays a significant role in the way in which

women are infected and affected and HIV/AIDS is the outcome of gender inequalities which is a feminist political agenda.

Among feminist writers, HIV and AIDS are best understood as socially, culturally, and ideologically as well as biologically determined phenomena. Nancy Goldstein (1997:5) wrote:

> Women's risks for HIV infection include poverty, racism, classism, sexism, incarceration, isolation, lack of access to medical care, illiteracy, homophobia, sex work, sexual abuse, domestic violence, alcohol and drug addition, and an ideology of heterosexual romance that demands that women do not question the fidelity of their male…

Feminist writers criticize the way in which HIV and AIDS are addressed in women. Most of the critiques are to do with women's representation in clinical trials, the early biomedical construction of HIV/AIDS, the risk classification (grouping) systems, medical and social research undertakings in relation to women and HIV/AIDS, and the interventions undertaken to prevent and control HIV/AIDS. Some of the core points are presented as follows:

- Women's participation in clinical trials in relation to HIV/AIDS was disproportionately low. The social, economic, gender inequality and structural issues that have placed women at the ever growing risk attracted little attention among western clinicians and researchers. The general perception of HIV was of a gay male issue, and "was attached to use of drugs, malnutrition, promiscuity, and homosexuality" (Rodriguez, 1997:34). Even when researchers began to include women in clinical trials, a large proportion of the participation was not to women's own benefit. Most of the trials were designed to decrease vertical transmission (mother to child transmission) of HIV which risks women's health and quality of life

for "the supposed assurance of HIV negative infants" (Murrian, 1997: 69).

- Researchers failed to recognize the disease in women and little attention was given about the ways in which HIV and AIDS affect women differently. Murrian (1997) argue that, even through women experience AIDS differently than men, the treatment of women with AIDS was based on the model developed almost exclusively from research on men. Also, scientific research and treatment were driven by drug companies whose primary purpose is to make a profit which had a clear influence on women.

- At the initial period, researchers failed to link poverty, economic hardship, or sexual oppression to the HIV/AIDS epidemic. Rather, according to Rodriguez (1997: 35); studies focused on "how much virus was present in different bodily secretions, and whether or not mosquito, tooth brushing, causal contact.... could lead to transmission... and in trying to identify where the virus came from..."

- HIV may provoke or escalate violence against women. Zeirler (1997) argued that women with HIV were dying at faster rate than men despite comparability in disease progression. This is because of lower socio-economic status, homelessness, domestic violence, substance abuse and lack of social support.

- Women living with HIV/AIDS are more likely to face violence from sexual partners or husbands. Pregnancy is an event in which women learn their HIV infection. Also, it is a time in which spouses of women may be more violently reactive. Thus, the context of pregnancy may increase violence from partners. Most women with

HIV are living in poverty; and their economic dependence on sexual partners makes it hard for them to walk away from a violent relationship particularly after an HIV diagnoses (Zeirler, 1997).

- Promotion of male condom largely ignored social, economic and gender inequality issues and male condoms had little relevance to the lives of women who are supposed to be at risk. Moreover, characterization of women as potential vectors for HIV infection enabled for the association of the disease with individual behavior and ignored the larger social forces that led the epidemic into women. As a result, HIV has proved to be "a disease carried primarily by social and political forces, along the lines of racism, gender inequality and economic oppression" (Rodriguez, 1997: 36).

- Public policy response to HIV/AIDS had often been to regulate women's sexuality by encouraging sex workers to use condoms and counseling young girls to delay and/or abstain from sex. Such responses inherently discriminate against girls and women, who may have little control over sexual decision-making (Long and Messersmith, 1998).

- Characterizations of high-risk groups were incomplete. The risk-grouping failed to recognize the underlying socio-economic determinants that place women at risk (Siegal and Burke, 1997). Any woman who practices unsafe sex (including those who are in monogamous marriages) is potentially vulnerable (Long and Messersmith, 1998). Older people have rarely been included on the lists of people "at risk" of HIV/AIDS though it is the behaviors (than ages) of people that puts them at risk. This is because of the assumption that older adults and the elderly are disengaged from

sexual activities. Older women's sexuality in particular is discounted and invisible (Siegal and Burke, 1997).

- Provision of the care of the ill has always fallen on women's shoulders both in health care institutions and at home. Grand mothers have often taken the responsibilities of raising their grand children due to AIDS. Thus, the burden of orphan crisis lies largely on older women (Long and Messersmith, 1998).

***Feminist Theory and Analysis of HIV/AIDS***

Feminist researchers have recognized that the socio-economic and biological complexity of HIV/AIDS has limited the prevailing theoretical and methodological approaches. A comprehensive prevention strategy requires a better understanding of gender relationships, women's roles and responsibilities in all aspects of life. As HIV/AIDS is primary transmitted through heterosexual sex, there is a need of understanding the gender relationships, male and female sexuality, and sexual practices (Long and Messersmith, 1998). However the issue of sexuality among women has remained obscure. Although knowledge and attitude studies had been undertaken, they could not analyze the most interesting aspects of HIV/AIDS and women including women's most intimate relationships, sexual practices and women's decision making on unsafe sex (Long and Messersmith, 1998).

It is also stressed that most analysis lacked the conceptual tools and frameworks to provide the broader understanding of the disease in women's lives. Quina (1997) wrote that HIV preventive behaviors have often focused on variables which presume personal control (e.g. health belief, self-efficacy) and group peer norms. However, applying the same methods and conclusions to women fails to take into account the social,

cultural and interpersonal variables which affect women's sexual and health related behavior (Quina, 1997). Long and Messersmith (1998) suggested that participatory methodologies and analyzing women's experiences are better in researches on women and HIV/AIDS which is also the particular focus of this study. They wrote:

> Feminist participatory methodologies, including analyzing women's experiences, locating the researcher on the same plane as the subject and doing research that benefits women could inform research and programmatic efforts on women and HIV/AIDS *(p.163).*

Feminist writers also stressed that HIV could not be prevented or managed without a better understanding of the political, economic, and social conditions that constrain women's full equality (Rodriguez, 1997). To address the epidemic, women living with and without HIV/AIDS need to work together. Women living with HIV/AIDS are "not only important sources of information about the disease, but also are catalysts for change in understanding the dynamics of HIV/AIDS transmission, prevention, control and support "(Long and Messersmith, 1998:163)**.**

# 3. METHODOLOGY

## 3.1 Design of the Study

In this study, qualitative methodology is mainly employed. This is because of the nature of the research itself. The aim of the study is to explore the socio-cultural and economic problems that are affecting women living with HIV/AIDS. It also aims at exploring women's experience with the virus which is difficult to quantify. Thus, the research topic as well as the research questions needs to be addressed mainly through qualitative study. Moreover, qualitative methodology is appropriate if one needs to study participants in their natural settings. This is one requirement that has to be fulfilled in undertaking research on women and gender issues (Creswell, 1998). Qualitative approach also enables the researcher to undertake deep exploration of the topic under study and to present the findings from participant's perspectives.

However, to get a comprehensive data and to measure specific aspects (variables) in relation to women and HIV/AIDS, quantitative tool of data collection (i.e. a questionnaire) is employed as a supplementary method. The questionnaire is designed to explore specific aspects like coping strategies, roles of women living with HIV/AIDS in prevention and control efforts and their critical needs. To this effect, the researcher triangulated both qualitative and quantitative tools of data collection: in-depth interviewing, focus group discussion and a questionnaire.

## 3.2. Area of the Study

According to reports from the Central Statistics Agency (2005), Addis Ababa has a population size of 2.97 million among which men account for 1.428 million (48%) and women 1.545 million (52%). Addis Ababa is a

home of various ethnicities; *Amhara* (48.3%), *Oromo* (19.2%), *Gurage* (17.5%), *Tigre* (7.6%), and others (7.4%). The religious composition of the city is; 82% Orthodox Christians, 12.7% Muslims, 0.8% Catholics and 0.6% others (CSA, 2005). The city is divided among ten sub-cites namely *Addis Ketema, Arada*, *Gulele*, *Lideta*, *Kirkos*, *Bole*, *Kolfe-keranio*, *Nifas silk- Lafto, Akaki-Kaliti*, and *Yeka.*

Among the ten sub-cities in Addis Ababa, Arada sub-city is selected for this study. This selection is made for two reasons. First, according to the sub-city's health department, the sub-city is severely affected by HIV as commercial sex work is widespread in the sub-city. Second, the overwhelming majority of the inhabitants is poor and is living in slum areas with poor sanitation and housing. Thus, in an attempt to access assistance, PLHA in the sub-city are more likely to disclose their HIV positive status to support institutions. Moreover, in the sub-city, home-based care giving is started prior to any other sub-city in Addis Ababa. For the reasons mentioned above, there was a possibility of getting significantly enough number of participants.

### 3.3 Participants of the Study

The target population for this study is mainly women living with HIV/AIDS in Arada sub-city. Moreover, home-based care givers and officials of intervening organizations (NGO officials) participated as supplementary sources of data. NGO officials are taken as target groups as the research needs to understand the kind of support provided to WLHA and the extent in which the problems of WLHA are addressed. Home-based care givers are incorporated because they have the understanding of the problems that are facing WLHA in their day to day lives.

### 3.4 Procedure of Data Collection

Before the actual data collection in the field, I contacted the Arada Sub-city Health Department through letters from the Institute of Gender Studies. With the assistance of sub-city's health department, I contacted with the Arada Sub-city HIV Secretariat and two health centers; Arada and Gulele which are under the jurisdiction of the sub-city's health department. The sub-city's HIV secretariat in turn officially requested two NGO's; Participatory Community Support Association (PCSA) and Hiwot HIV/AIDS Prevention, Care and Support Organization (HAPCSO) for collaboration. The two NGO's then accessed the participants for the researcher.

Both PCSA and HAPCSO are purposefully selected for this research. These organizations provide home-based care services and food aid for PLHA in the sub-city. PCSA and HAPCSO, in addition to home-based care services, provide support for orphans and vulnerable children. The two NGO's are purposefully selected for the reason that they accommodate a significant number of beneficiaries in the sub-city.

### 3.5 Instruments of Data Collection

The researcher has employed, as stated before, both qualitative and quantitative tools of data collection. They are; in-depth interviewing, focus group discussion and a questionnaire. The justification of instruments of data collection is presented as follows.

#### 3.5.1 In-depth Interviewing

In this study, in-depth interviewing is employed as a major tool of data collection. Individual in-depth interviews were conducted among women

living with HIV/AIDS. To understand the extent in which the needs and problems of WLHA have been sufficiently addressed, key informant interviews were conducted among home-based care givers and officials of intervening organizations.

A total of 14 women living with HIV/AIDS were purposefully selected to participate in the in-depth interviewing. Age, marital status and having or not having children are included in the selection criteria of women participants. The researcher focused on women with low income. This is because it is very difficult to contact HIV positive women with high level of income as they do not need the support of NGOs. Those poor and vulnerable women who have no choice rather than surviving through food aid are the primary beneficiaries of the services of NGO's as well as participants in this study.

Ten open ended guiding questions were prepared for WLHA. They were asked to explain their personal biography (i.e. age, place of birth, marital status, religion, level of income, children etc). They were also asked about the challenges they encountered from family members, friends, and neighbors and generally from the society. They were asked to compare and contrast their lives before and after they have known their HIV positive status. They were also asked about their experiences of stigma and discrimination, coping strategies, their needs, the quality of support they were getting from organizations and their roles in the prevention and control of HIV (See Appendix I).

Women with the virus were interviewed in their own home. The researcher himself has undertaken the interview with the assistance of female home-based care givers. In the process of accessing entry to the setting of the participants, the researcher realized that home-based care givers were the appropriate gatekeepers. Their role in this study thus

ranged from accessing the participants to assisting the actual data collection. I frequently visited the participants before conducting actual data collection.

In the key informant interviews, a total of eight participants were selected. Among these, 4 (2 men, 2 women) were home-based care givers and 4 (2 men, 2 women) officials of NGOs. Half of them were selected from PCSA and the rest half from HAPCSO. Regarding participants from PCSA and HAPCSO officials, ten guiding questions were addressed. The questions mostly dealt about their roles in minimizing the problems of WLHA (see Appendix III). For home-based care givers a total of eight guiding questions were addressed (see Appendix IV). Interviews conducted with officials of NGO's and home-based care givers were made through appointments and in places where they themselves wanted.

### 3.5.2 Focus Group Discussions

In this research, focus group discussion is the second major tool of data collection. Focus group discussions were conducted among twelve women living with HIV/AIDS. Two focus group discussions were employed among WLHA. Each group had 6 members. Half of them were selected from PCSA and the rest half from HAPCSO. Six guiding questions were prepared for the FGD which focused on problems encountered by WLHA, factors contributing to women's vulnerability to HIV, coping strategies and their effectiveness, critical needs of WLHA and roles of WLHA in the prevention and control of HIV/AIDS. In addition, participants were asked to give their suggestions and comments on how to better address their needs (see Appendix II). The discussions were undertaken at Minelik I primary school where community communication programs are undertaken. The beneficiaries of the NGOs particularly of PCSA are the prominent participants of the programs held at Minelik I primary school. The researcher himself has been

participating in the programs for months and he is acquainted with most of the participants. The researcher used tape recorder to collect data from the FGDs. All participants were interviewed with the Amharic language.

### 3.5.3 The Questionnaire

In this study, a questionnaire is employed as a supplementary method of data collection. It was administered among women living with HIV/AIDS in Arada sub-city. It was first written in English, translated into Amharic and then translated back to English to ensure the accuracy and consistency of wording. Some of the specific variables in the questionnaire are presented as follows.

***Respondents' Socio-economic and Demographic Status***

The respondents were asked to inform their ages, level of education, marital status, religion, level of income, employment status, number of children, housing condition etc. This gives brief information on the respondents' personal background.

***Respondent's Experience with HIV/AIDS***

Respondents were asked about what month and year they were diagnosed and the factors that might have exposed them to the virus. Then they were asked to report whether they have disclosed their HIV positive status. If they answered affirmatively, they were asked to inform to whom they had disclosed. Then, they were asked to inform the problems they encountered at home, in work places and generally in the society. The questions were presented in three independent tables to treat problems encountered at home, at work places and in the society independently. Finally respondents were asked their opinion on the

reason why the society stigmatizes or discriminates PLHA. Moreover, to explore the positive experiences of WLHA, respondents were asked what advantages they have got from disclosing their HIV positive status.

***Coping Strategies***

In this category, respondents were asked about what strategies they had been employing in order to cope up living with the virus. A total of twelve items were prepared based on literature on coping strategies that PLHA employ in different countries. The last item asks respondents to specify any strategy (if they have) that they use to cope up with HIV/AIDS. The items were responded on two point scales “Yes” and “No”.

***Critical Needs of WLHA***

Respondents were asked to inform their major needs. A total of ten items were prepared in this category. The items incorporated emotional, physical, socio-economic and health care needs of participants. These needs are measured with respect to three scales (1) high, (2) medium and (3) low.

***Roles of Intervening Organizations***

In this category, respondents were asked to inform whether they are getting assistance from institutions. Then, they were asked to specify the kind of the organization. They were also asked to specify the kind of support they are receiving from six items provided. Respondents were also asked to evaluate the support and to inform how this assistance helped them.

***Roles of WLHA in the Prevention and Control Efforts***

In this category, respondents were asked whether they participate in the prevention and control of HIV/AIDS. If they responded affirmatively, they

were asked to specify the kinds of roles they are playing from six items. The items were responded on two point scales “Yes” and “No”.

#### 3.5.3.1 Sampling Procedure

As said before, the questionnaire is employed as a supplementary method of data collection. Thus, a small sample size is employed as it is difficult to get a large number of participants. The rate of disclosure of one’s positive status is low in Ethiopia for various reasons. Thus, a total of 200 questionnaires were distributed among WLHA who were beneficiaries of PCSA and HAPCSO, and health attendants at two health centers in Arada sub-city. Among the questionnaires distributed, a total of 184 (92%) questionnaires were responded. A pilot study was undertaken among twenty participants with similar audience and some adjustments and modifications of the questionnaire were undertaken.

The researcher has purposefully chosen four sites to collect data through the questionnaire. These are two NGOs, namely PCSA and HAPCSO and two health centers; Arada and Gulelle health centers. The two health centers are under the jurisdiction of Arada sub-city and health attendants (who are HIV positive) in the sub-city are mostly referred to these sites. Gulelle health center has health attendants from other sub-cities and the questionnaire was administered among those who were from Arada sub-city. In each of the four sites, 50 questionnaires were distributed. In the two health centers, nurses and their assistants filled the questionnaires. They were given briefings about the questionnaire and its administration before they started actual data collection.

Determination of participants through a sampling frame was impossible for various reasons; inaccessibility of participants (WLHA), limited rate of disclosure among many of them and lack of willingness to participate in

studies among some of the participants. Thus, any HIV positive woman health attendant was eligible to participate in the survey. To avoid the overlapping of respondents, the card numbers of the health attendants' files were written on each questionnaire.

In PCSA and HAPCSO, the questionnaires were filled through home-based care givers. Ten home-based care givers were randomly selected from each of the NGOs. Each was given five questionnaires to interview their own clients. But some of them had more than five clients and some others less. Some had entirely male clients, but rarely. In such situations, some other ones were employed in place. Home-based care givers were also provided sufficient orientation on how to fill the questionnaire by the researcher himself. More importantly, the researcher himself supervised the whole process of data collection through the questionnaires at all sites. Data collection for the survey lasted for a month (from 15 October to 15 November 2006).

### 3.6 Data Analysis

In this study, data are analyzed both qualitatively and quantitatively. In the process of analyzing qualitative data, categories or themes of analysis were determined first. The categories or themes were determined based on the combination of the research questions, objectives of the study, the questions asked to the participants and the data itself. Determining analytical themes began with deep reading of data. Based on the analytical categories, information from focus group discussions and in-depth interviews was merged. Then, cases were prepared according to the analytical categories. Based on the cases prepared, a detail interpretation was undertaken.

Quantitative data are analyzed using SPSS (Statistical Package for Social Sciences). SPSS analysis was used to calculate frequencies and percentages to all questions. Open-ended questions in the questionnaire were coded, edited and entered in to computer for analysis. Finally, data from interviews, group discussions and the survey are merged and presented together. Only the socio-economic and demographic backgrounds of the participants in the three tools of data collection were treated independently. Tables are used to present the findings in the survey.

# 4. FINDINGS

## 4.1 Background Characteristics of Participants

In this section, the socio-economic and demographic background of participants in both qualitative and quantitative study (in-depth interviewing, focus group discussion and the survey) is presented. Some of the background characteristics presented include: age, level of education, marital status, religion and housing condition. The description of background characteristics is presented for the reason that it is easier to understand about whom the study was. It also enables readers to easily comprehend the findings and to interpret the result of the study.

### 4.1.1 Background Characteristics of Interview Participants

In-depth interviewing is the first major method employed in this study. In-depth interviews were conducted among fourteen women living with HIV/AIDS. As stated in the methodology section, half of the participants were selected from PCSA and the remaining half from HAPCSO. The age distribution of participants ranges from 21-58 years. There was only one participant in the age group 15-25, eight participants in the age group 26-35 and, five participants in the group of 36 years and above. Half of the participants had one or more children; the other half did not have children. None of them was engaged in formal employment. Regarding the level of education of participants, three of them had secondary education while six participants had primary education. The remaining five did not have any education.

Eight of the participants (57%) were living in rented houses. Three of them were living with their parents. One participant was sharing a house

with her friends. One other was living in the streets being kicked out from home by the family. Only one participant had her own house. Thirteen of the participants were Orthodox Christians. There was only one Muslim participant in the interview. All, participants received assistance from either PCSA or HAPCSO. The participants' time since diagnosis ranged from one to ten years. The following table describes the participants' background information.

**Table 1. Background Characteristics of Interview Participants**

| Name* | Age | Housing Condition | No. of Children | Formal Employment | Education Level | Time since Diagnosis | Religion |
|---|---|---|---|---|---|---|---|
| **Alemitu** | 30 | Rent | 5 | No | Primary | 2 | Orthodox |
| **Sara** | 37 | Rent | 1 | No | Primary | 5 | Orthodox |
| **Emebet** | 30 | Rent | - | No | Illiterate | 2 | Orthodox |
| **Zerfie** | 55 | Rent | 4 | No | Illiterate | 3 | Orthodox |
| **Wudie** | 58 | Rent | 5 | No | Primary | 1 | Orthodox |
| **Zeynaba** | 33 | With Parent's | 1 | No | Primary | 8 | Muslim |
| **Almaz** | 27 | Sharing with others | - | No | Primary | 3 | Orthodox |
| **Tirfie** | 27 | With Parent's | - | No | Primary | 4 | Orthodox |
| **Mekdes** | 28 | With Parent's | 2 | No | Primary | 10 | Orthodox |
| **Tizita** | 21 | Rent | - | No | Illiterate | 3 | Orthodox |
| **Konjit** | 29 | Rent | - | No | Secondary | 2 | Orthodox |
| **Hanna** | 28 | Street | - | No | Secondary | 8 | Orthodox |
| **Hiwot** | 38 | Rent | - | No | Secondary | 5 | Orthodox |
| **Getenesh** | 40 | Own | 4 | No | Illiterate | 2 | Orthodox |

** All the names mentioned are pseudonyms*

### 4.1.2 Background Charactertics of Focus Group Discussants

Focus group discussion is a second major source of data for this study. As stated in the methodology section, two group discussions were

conducted. All of the participants in the FGDs were women livening with HIV/AIDS. All of them also receive assistance either from PCSA or HAPCSO. Half of them were selected from PCSA and the rest from HAPCSO.

The ages of the participants of FGD ranged from twenty one to forty five. Eight (out of twelve) had one or more children. Three of the participants had secondary education. Four of them had primary schooling. The remaining five were illiterate. None of them had formal employment. Table 2 describes the characteristics of FGD participants in the first group.

**Table 2. Background Characteristics of FGD Participants**

| Name* | Age | Level of Education | Formal Employment | Marital Status | No. of Children | Time Since Diagnosis (Years) | Religion |
|---|---|---|---|---|---|---|---|
| **Mihret** | 45 | Illiterate | No | Currently married | 4 | 2 yrs | Orthodox |
| **Kabtish** | 41 | Illiterate | No | Widowed | 3 | 5 yrs | Orthodox |
| **Seble** | 23 | Primary | No | Single | - | 1 yrs | Protestant |
| **Rekia** | 35 | Illiterate | No | Currently married | 4 | 2 yrs | Muslim |
| **Meseret** | 28 | Secondary | No | Single | - | 3 yrs | Orthodox |
| **Atsede** | 31 | Primary | No | Separated | 2 | 3 yrs | Orthodox |
| **Zinash** | 38 | Illiterate | No | Currently married | 4 | 2 Yrs | Orthodox |
| **Solome** | 28 | Primary | No | Widowed | 2 | 3 yrs | Orthodox |
| **Gennet** | 36 | Primary | No | Widowed | 1 | 8 yrs | Orthodox |
| **Hirut** | 32 | Illiterate | No | Single | - | 5 yrs | Orthodox |
| **Senait** | 21 | Secondary | No | Single | - | <1 yr | Orthodox |
| **Kuri** | 25 | Secondary | No | Separated | 2 | 2 yrs | Orthodox |

** All the names mentioned are pseudonyms*

### 4.1.3 Background Characteristics of Participants in the Survey

As stated in the methodology section, the total of number of participants covered in the survey is 184 women living with HIV/AIDS. Regarding the age distribution of the respondents, 59.9 percent were in the age category of 25-35 years, 26 percent were above 35 years and the rest (14.1 percent) were in the age group 15-24. Regarding the level of education of the respondents, 23.5 percent had no education and 9.2 percent could read and write. A total of 38.6 and 27.2 percent of the participants had primary and secondary education respectively. Only 1.6 percent of the participants responded that they had higher education.

Concerning the marital status of the respondents, 26.2 percent of the respondents were never married. Only 27.3 percent were currently married. More over, 20.3 percent of the respondents were divorced. The remaining (26.2 percent) were widowed. The majority of the respondents (87 percent) were followers of Orthodox Christianity, 6.5 percent of the respondents were Muslims and 6 percent were followers of Protestantism. The rest (0.5%) were followers of other religions.

The majority of the participants (93.4 percent) responded that they were not engaged in formal employments. Only 6.6 percent were engaged in formal employments. Among those participants who were not engaged in formal employments, 48.8 percent were engaged in casual (on daily basis) works, 43 percent were house wives, 4.1 percent were pensioners and the remaining (4.1 percent) were engaged in other activities.

Most of the participants of the survey (66.1 percent) responded that they had children. Among those participants who responded that they had children, 37.2 percent responded that they had only one child each, 37.2 percent two children and 14.9 percent responded that they had three

children. The rest (10.7 percent) of the participants responded that they had four or more children.

Regarding the housing condition of the participants, the majority (58.9 percent) responded that they were living in rented houses. Among those participants who responded that they were living in rented houses, 24.6 percent responded that they were rented from private and the remaining (34.3 percent) form kebele. 16.6 percent of the participants responded that they were living with their parents. Only 6.5 percent have their own houses. The following table shows the socio-economic and demographic background of participants in the survey.

**Table 3. Socio-economic and Demographic Background of Participants in the Survey**

| Item | Level | Frequency | Percent |
|---|---|---|---|
| **Age** | 15-24 | 26 | 14.1 |
| | 25-35 | 110 | 59.9 |
| | 36+ | 48 | 26.0 |
| | Total | 184 | 100 |
| **Education** | Illiterate | 43 | 23.5 |
| | Read and Write | 17 | 9.2 |
| | Primary (1-8) | 71 | 38.6 |
| | Secondary (9-12) | 50 | 27.2 |
| | Higher Education | 3 | 1.6 |
| | Total | 184 | 100 |
| **Marital Status** | Never Married | 48 | 26.2 |
| | Currently Married | 50 | 27.3 |
| | Divorced | 37 | 20.3 |
| | Widowed | 48 | 26.2 |
| | Total | 183* | 100 |
| **Religion** | Orthodox | 160 | 87.0 |
| | Protestant | 11 | 6.0 |
| | Muslim | 12 | 6.5 |
| | Other | 1 | .5 |
| | Total | 184 | 100 |
| **Formal Employment** | Yes | 12 | 6.6 |
| | No | 170 | 93.4 |
| | Total | 182* | 100 |
| **Average Monthly Income for Employed** | 210-400 | 9 | 75.0 |
| | 401-800 | 2 | 16.7 |
| | 801+ | 1 | 8.3 |
| | Total | 12 | 100 |
| **Status of Formally Unemployed** | House wife | 74 | 43.0 |
| | Pensioner | 7 | 4.1 |
| | Casual worker | 84 | 48.8 |
| | Other | 7 | 4.1 |
| | Total | 172 | 100 |
| **Do you have children** | Yes | 121 | 66.1 |
| | No | 60 | 33.9 |
| | Total | 181* | 100 |
| **Number of Children** | One | 45 | 37.2 |
| | Two | 45 | 37.2 |
| | Three | 18 | 14.9 |
| | Four and Above | 13 | 10.7 |
| | Total | 121 | 100 |
| **Housing Condition** | Rented from private | 45 | 24.6 |
| | Rented from Kebele | 63 | 34.3 |
| | Private | 12 | 6.5 |
| | Parent's | 31 | 16.6 |
| | sharing with others | 12 | 6.5 |
| | Other | 21 | 11.5 |
| | Total | 184 | 100 |

** Missing Responses*

## 4.2 Vulnerability

The factors that make women more vulnerable to HIV infection are diverse and complicated. They encompass social, cultural, economic, biological, political and legal issues that are closely interrelated to one another. In this section, poverty is discussed as a major cause for women's vulnerability in combination with sexual abuse, lack of appropriate healthcare services and rural-urban migration.

Poverty is a major factor that makes women more susceptible to HIV infection. It is true that the majority of the poor in the world are women. Women account for about seventy percent of the poor globally (Collins and Rau, 2000). This is attributed to different factors. In many societies women have limited access to and control over economic resources compared to men. Moreover, women are disproportionately represented in the public work force. Those women who are formally employment have disadvantageous and less honorable positions (Yosufi, 1997). They are also less paid compared to men. Women have limited participation in education and decision making activities. These factors have then led to the global feminization of poverty.

Poverty and HIV/AIDS are closely related. One can be the cause for the other. A woman who is poor is more vulnerable to HIV infection. Also, a woman with HIV/AIDS is more likely to be poor (Collins and Rau, 2000). HIV intensifies poverty and even pushes non-poor to poverty. When we look in to the lives of women living with HIV/AIDS, we can visibly understand how poverty puts them in to risky relationships. A participant describes how she could have been infected with HIV as follows.

> I was married at the age of fifteen to a man who was a wage earner. I delivered five children from him. After living together for about thirteen years, he died in an occasional

> illness. Upon his death, I was frequently sick and did not have the physical strength to work as a laborer. Thus, I could not feed my children and I started commercial sex work. It might have been then that I caught HIV. (Getenesh, Age 40)

The woman's words can best explain the close relationship between poverty and vulnerability. Commercial sex work is a survival strategy for those women who have no alternative opportunities for their livelihood. Literature has shown that many commercial sex workers accept clients who refuse to use condoms due to economic problems. Qualitative data confirms this fact. Group discussants informed that women feel a sense of responsibility of raising their children and in order to accomplish this responsibility, they may engage themselves in risky relationships. Women with children are highly worried about how to feed them today. They are not concerned about risks. Thus, economic constraints are the factors that make women unable to distant themselves from risky relationships. Participants also argued that women are forced to tolerate their husband's risky behaviors for fear of rejection and violence. Women's economic dependency on men has made them unable to cope up with the economic challenges if their husbands reject them.

Poverty is added to other 'push' factors in rural areas resulting from rural–urban migration. Migration is one livelihood strategy particularly for young people in the underdeveloped world (Collins and Rau, 2000). Poverty forces young women to migrate to urban areas in an effort to seek better economic opportunities. The lives of commercial sex workers who have ended up in HIV infection tell how poverty driven rural-urban migration had forced them to engage in risky relationships. A woman described her life story as follows.

> I was born in Wadla Delanta, Wello. I came to Addis Ababa at the age of fifteen without identifying the good and the evil. My parents were poor. I worked as a servant in different

> houses. But all people I encountered were not good. In a certain house, my employer beat me on my head. After staying in this work for about six years, I left it and stared commercial sex work. (Emebet, Age 30)

In addition to poverty, socio-cultural pressures on women push them to migrate to urban areas by then increasing their vulnerability. Some of the socio-cultural pressures include early marriage, wife inheritance, arranged marriage and women's lack of inheritance and land ownership rights. A discussant stated:

> In some communities of rural Ethiopia, women are forced to marry their brother-in-laws. There is also arranged marriage in which girls are forced to marry a man whom they do not know. Due to this, young girls prefer to migrate to urban areas. Good things do not wait for these young women in urban areas. They mostly are seen engaging in commercial sex work. (Zinash, Age 38)

Poverty also in some cases serves as a ground for sexual abuse and increases the risk of HIV infection among women. The experience of some of the participants in this study strengthens this fact. Poor women who had worked as housemaids have reported that they had frequently encountered sexual abuse that resulted from HIV infection. One participant reported her experience of sexual abuse as follows.

> I worked as a housemaid in different houses. But in most of the houses, I encountered sexual violence. Most of the men, including those who had wives, used me to satisfy their sexual desires. Specially, there was a man who used to come to my bedroom daily after his wife went asleep. He had five children. He and his wife had separated their sleeping rooms for the reason I did not know. One day, as he was sleeping with me in my bedroom, his wife awakened hearing my weep. She came near my bedroom and asked me to open the door. But he locked it from inside. She said that she would kill me the next day and went back to her bed. Did he go back to his room? No, he stayed the whole night with me… The next day, I carried all my baggage and left out of their

> house. I stayed for only fifteen days in this house. But the man raped me almost in all of those days. Finally, I got pregnant. I went back to the man and asked him to give me some money for abortion. He gave me 150 birr. Then I aborted. After four months, I heard that he had died. Then, I decided to take a blood test and I found that I caught HIV. (Almaz, Age 27)

Poverty is also a determining factor on the quality of healthcare service that people acquire. It is visible that socio-economic status directly correlates with access to quality healthcare services. Poor women are less likely to have access to quality healthcare services. Lack of access to quality healthcare services means that poor women could be at high probability of encountering blood contamination. An old woman participant reported that she might have caught HIV from unsafe healthcare services:

> I do not certainly know how I caught this disease [HIV]. I stopped relationship [sexual relationship] sixteen years ago. I have never seen a man within these years. But there was one event that I suspect I might have caught this disease. Once, I was suffering from wounds and sores on my face. That time, I visited a certain traditional healer. He used to treat many people. He wore a glove for himself and used to put medicine to many people who had wounds with out changing his gloves. This must be a cause for the disease in me. I did not have the understanding of how AIDS catches people. It is only after I caught it that I understood how it comes to people. (Zerfe, Age 55)

The woman's words, in addition to reflecting the role of low access to healthcare services for increasing one's vulnerability to HIV, confirms with the fact that older women have relatively lower knowledge on how to protect themselves form HIV. Quantitative data shows that 26 per cent of the participants of the survey were aged above 35 years. This shows that there are a relatively large number of older women living with HIV. Older women are considered as "less vulnerable" to HIV infection. This is

because there is an assumption that they are not sexually active and, compared to the youth, are less likely to engage in risky relationships (Siegal and Burke, 1997). This has made HIV among older women invisible.

Literature on older women and HIV/AIDS has shown that older women, as they had been considered as less vulnerable, were less addressed in the awareness creation campaigns. It is only recently that efforts were begun to incorporate this section in to the campaigns through community communication programs (CCP). But still, older women are less likely to attend education programs for various reasons. In the programs I myself participated, there were few older women attendants. Also, those who occasionally visit such programs did not participate regularly. Even those women with HIV are highly reluctant to visit CCPs. Their absence has bothered the NGOs and they used to frighten women that they would quit their assistance if women were not participating regularly in the CCP.

There are reasons why women were not active participants of the CCPs. One is that most women have household responsibilities. Moreover, in many cases, older women frequently attend prayers particularly on Saturdays and Sundays. The CCPs are usually held on Saturdays or Sundays in which older women attend prayers. As a result, they may be deficient of having enough knowledge of HIV. The fact that they are the principal providers of care and support to the sick is added to their limited knowledge of prevention of HIV and these make them vulnerable to HIV infection.

In general, poverty is closely interrelated with socio-cultural factors and as a result is the major factor that put women and young girls at a high

risk of infection. Poverty, in addition to the lower social status of women, has made women not to negotiate safe sex and not to question their husbands' fidelity.

### 4.3 Socio-cultural Problems

#### *Women's Experience of Stigma*

Both qualitative and quantitative data show that women face stigma at home, at work places and generally in the society. Stigma prevails in different forms. It has also a variety of causes. The consequences of stigma on the lives of women are diverse and severe. Participants in both interviews and group discussions argue that people with HIV still face stigma and discrimination. A participant explains her experience as follows:

> As my families found that I am HIV positive, they put me inside a small room so that I could not have any contact with family members. When neighbors came to visit me, they used to say; 'she is not around'. Later, our neighbors became suspicious of my HIV status and they stopped to drink coffee in our home. All my body was full of sores and wounds and no one was willing to approach me. But, when I started to take the ART, I have recovered. Now our neighbors are gossiping that I had not HIV and I was deceiving them. (Mekdes, Age 28)

Data from focus group discussions show that women with HIV are more likely to face blame and violence from their partners after HIV positive diagnosis. It is true that either of the two could bring HIV to the family; but gender inequality has made women to be blamed more harshly than men (Nyblade et al, 2003; Johnson, 2002). The data shows that most women found their HIV status when they are pregnant or when they plan to go to abroad. So, if the husband discovers his wife's HIV positive status, he is more likely to be violent against her. Thus some women,

even though they found their HIV positive status, do not inform to their partners for fear of violence, rejection, separation and blame. Such silence has a severe effect on the health status of the family. The data shows that there are pregnant women who do not take care of their fetus as well as the newly born children for fear of violence and blame from their husbands. A discussant said:

> Whoever brings the virus to the family, it is women who are always blamed. There are many women who encounter problems from their husbands in their respective homes. When you see the outside, it seems stigma is decreasing. But, among women, it is still there. (Solome, Age 28)

Stigma has also forced women with HIV not to disclose their status to the general public. Most of the participants in the interview and the group discussions informed that they have not still disclosed their status to the general public for fear of stigma. The survey result also confirms this fact. It indicates that only 9.2 percent of the respondents have disclosed their HIV positive status to the general public. A discussant said:

> I won't tell anyone that I have AIDS. Because I have seen people stigmatized. In our area, there is a notable man who is about 60 years old. He went to Arsho Clinic and was told that he has HIV. He has a villa house and many children. All his children stigmatized him. No one is approaching him among his own children. There is no one to provide care for him. His wife died a year ago. He used to rent rooms in his compound and when the renters found that he has HIV, all of them left the house. His children built a block half way in the compound. They made two gates for the compound_ one for their father and the other for themselves. This happened only recently. (Mihret, Age 35)

The following table shows the participants' experience of stigma within family members.

**Table 4. Stigma Experience of Participants within Family Members**

| Item | Answer | Frequency | Percent |
|---|---|---|---|
| **Blamed for being promiscuous** | Yes | 57 | 40.7 |
| | No | 83 | 59.3 |
| | Total | 140* | 100.0 |
| **Faced emotional violence from family members** | Yes | 51 | 36.4 |
| | No | 89 | 63.6 |
| | Total | 140* | 100.0 |
| **Chased out from home** | Yes | 29 | 20.7 |
| | No | 111 | 79.3 |
| | Total | 140* | 100.0 |
| **Separation of eating utensils** | Yes | 52 | 37.1 |
| | No | 88 | 62.9 |
| | Total | 140* | 100.0 |
| **Not allowed to participate in housework** | Yes | 49 | 35 |
| | No | 91 | 65 |
| | Total | 140* | 100.0 |

** Participants who disclosed their status to family members and experienced stigma*

Data from the survey shows that participants experienced stigma and discrimination within family members, coworkers and in the society. However, only a small proportion of the participants responded to the questions on particularly stigma at work places and at societal level as most of them had not disclosed their status to the general public. From among the participants that disclosed their HIV status to family members, 40.7 percent responded that they were considered as promiscuous by family members. More than 36 percent of the participants responded that they faced emotional violence from family members. About 37 percent responded that their utensils were separated. Participants also responded that they were prohibited from participation in house work (35 percent) and chased out of home by family members (20.1 percent) (See Table 5).

Participants in the qualitative study informed that though they do not disclose their HIV status, neighbors and friends might be suspicious and stigmatize them. One way in which other people could be suspicious is the fact that the participants receive support from organizations. If a woman is seen in and around PCSA, she is more likely to be considered as HIV positive. And, gossip and voyeurism follows. Most of the participants argue that their status is almost known to neighbors as they are either visited by home-based care givers or are seen receiving food support. A young woman participant said:

> My ear always catches the talks of my women neighbors saying; 'She has AIDS. We saw her at the organization. Also she laughs as a healthy person… These days this prostitute goes here and there. She might have planned to infect our men with her disease'. They always throw bad speeches on me whenever they see me. They have prohibited their children not to approach me warning that I would infect them if they do so. Accepting their parents' advise, the kids insult me saying; 'Anchi Aydsam'- You a person with AIDS. (Tizita, Age 21)

**Table 5. Stigma Experience in the Society**

| Item | Level | Frequency | Percent |
|---|---|---|---|
| **Abandoned by neighbors** | Yes | 38 | 65.4 |
| | No | 20 | 34.5 |
| | Total | 58* | 100.0 |
| **Chased out from rental houses** | Yes | 11 | 19.0 |
| | No | 47 | 81.0 |
| | Total | 58* | 100.0 |
| **Denied healthcare services** | Yes | 15 | 25.9 |
| | No | 43 | 74.1 |
| | Total | 58* | 100.0 |
| **Loss of respect from the society** | Yes | 39 | 67.2 |
| | No | 19 | 32.8 |
| | Total | 58* | 100.0 |
| **Differential treatment in public places** | Yes | 27 | 46.6 |
| | No | 31 | 53.4 |
| | Total | 58* | 100.0 |

**Participants who disclosed their status to the society and experienced stigma*

Data from focus group discussions show that WLHA face severe stigma when they get pregnant. This stigma is attached to the traditional consideration of women with the virus as "vectors" that transmit HIV to their children and husbands. This has been perpetuated by gender inequality and women's lower socio-economic status. In the first place people living with the virus are expected (by the society) to stop any kind of "pleasure" including sex. They are also expected to stop "this worldly" concerns such as marriage, child delivery and enjoyment. In turn, they are expected to attend prayers, to fast, to attend holy waters and to do all things that are supposed to grant salvation. They have to be prepared for the "other life" as they are "going to it sooner". Negative perceptions are attached to these beliefs. A discussant said:

> Some people do not expect us to be happy. They also do not think that we make sex and get pregnant. They do not think we can deliver children. I was pregnant two times after I have known my HIV positive status. Many people were speculating that the baby would not have either hands or legs, or would be blind. When I tried to explain the reality, they did not understand me. They rather say to me 'you who have AIDS do not think properly, your minds are not normal'. They believe that HIV disorients mentality. (Mihret, Age 35)

Another discussant said:

> When I got pregnant two years ago, my neighbors said; 'she is not afraid of God. She has got pregnant once again. How is she going to deliver it?' But I had good understanding and I took the medicine [prevention of MTCT]. I went to Black Lion Hospital and delivered a girl normally. The next day, I went to my home holding the baby in my hands. They all were surprised. They could not believe their eyes. I took the baby after three months to the hospital for check up and it is negative. (Getenesh, Age 40)

The women's speech shows how the people lacked sufficient knowledge about HIV and AIDS. This is the manifestation of failure of prevention efforts in providing sufficient understanding on HIV and AIDS to the people at all ages. Participants in the survey believed that people stigmatize those who live with the virus due to lack of sufficient knowledge about HIV and AIDS (89.6 percent), because people do not recognize their stigmatizing actions (85.2 percent), because people with the virus are considered as promiscuous (55.7 percent), fear of death (62 percent), and because HIV is considered as God's curse (52.2 percent). The following table shows participants' opinion on the reasons behind stigma against PLHA.

**Table 6. Participants' Opinion on the Reasons Behind Stigma against PLHA**

| Item | Answer | Frequency | Percent |
|---|---|---|---|
| **Lack of sufficient knowledge about HIV and AIDS** | Yes | 164 | 89.6 |
| | No | 10 | 5.5 |
| | Don't know | 9 | 4.9 |
| | Total | 183* | 100.0 |
| **Fear of death from AIDS** | Yes | 114 | 62 |
| | No | 51 | 27.7 |
| | Don't know | 19 | 10.3 |
| | Total | 184 | 100.0 |
| **Because people with the virus are considered as promiscuous** | Yes | 102 | 55.7 |
| | No | 26 | 14.2 |
| | Don't know | 55 | 30.1 |
| | Total | 183* | 100.0 |
| **Because HIV is considered as a curse from God** | Yes | 96 | 52.2 |
| | No | 68 | 40 |
| | Don't know | 20 | 10.8 |
| | Total | 184 | 100.0 |
| **Because people do not recognize their stigmatizing actions** | Yes | 156 | 85.2 |
| | No | 11 | 6.0 |
| | Don't know | 16 | 8.7 |
| | Total | 183* | 100.0 |

**Missing One Response*

As it is discussed before, stigma still prevails influencing the emotional, social and economic situations of women. Many PLHA are facing stigma and discrimination at different settings. However, those WLHA who have lived with HIV for longer periods argued that there had been improvements in the extent in which people with HIV had been treated. A discussant who lived with HIV for ten years said:

> As people found my HIV positive status, they severely stigmatized me. For about eight months, I did not have any contact with people around me. They used to harass me with irony speeches from dawn to dusk. I used to cry whenever they threw words at me. Now I do not care about whatever they say. I even laugh and directly tell them that HIV can not be transmitted through shaking hands and eating together. In fact some people have been changed. (Gennet, Age 36)

Another participant said:

> I am still stigmatized by my families. I still do not eat or share bed with them. But I can say that they have been changed to some extent. This is because they have at least resigned from firing me out of home. I am also not bothered about what people talk about me. Only those who are newly infected are in a problem. They are sensitive to what people talk about them. I know many people who had facilitated their own death and shortened their lives because they always were in anger and stress. You have high probably of dying sooner if you are stressed and angered,. Currently I am emotionally strong. I discuss about my worries with people like me and get solutions. (Sara, Age 37)

From the words of the women, it is possible to say that it is not only the peoples act of stigma that has been changing, but also PLHA themselves have developed their own strategies to cope up with external pressures. As people live for longer period of time with the virus, they are able to develop assertiveness and demonstrate that "it possible to live like others who do not have HIV" as many of the participants are fond of saying. Moreover their assertiveness arises from the networks they have created with other PLHA and the counseling services they receive from organizations and friends.

The survey result also supports the fact that the people's stigmatizing actions have been decreasing. That is; 57.6 percent of the participants responded that there were improvements in the way they had been

treated by their family members. Regarding the reasons behind such improvements, the majority of the participants agreed that it is due to the increase in awareness in the society and increase of their income from institutional assistance.

***Self-Isolation***

Qualitative data shows that, women with HIV isolate themselves from social networks, religious associations and from community activities either for fear of stigma or because of experiencing stigma. In some cases, they prefer to distance themselves from community events and coffee ceremonies in which women are the prominent participants. A participant said:

> I first told my HIV status to my nearest friend as a secrete. But she informed to all people in our area. I quarreled with her. There is no one who is not informed about my status because of that evil woman. I was a member of 'Aboye Tadiku Tsebel' [a religious association]. I resigned from it. But in spite of her evils, my neighbors are good. They did not forbid me from membership. I myself left it. They even sympathize me as I am a mother of four children whose father is dead. Only that woman with a snake tongue was dangerous to me. (Getenesh, Age 40)

Another participant said:

> I have told my positive status only to my mother. I have not told it to my brother because I am afraid that he may tell to my neighbors. But my neighbors always suspect my status because they know that I dropped my plan to go to an Arab country. Many times, they comment over my body, saying 'you are getting thinner'. One day I caught my neighbor staring at my body through a hole of the door. Another neighbor said to me 'let God give you long life and health' which means 'you may die soon'. These situations angered me and I stopped to talk any word with them. I still do not drink coffee with them. Even I warned my mother not to reach their quarters. (Tirfie, Age 27)

Some participants informed that they themselves limit their relationships with other people. This is because they feel that other people may not be comfortable to have physical contacts with them. Thus, to avoid such discomfort, some people who live with the virus restrain from having physical contacts with other people. A participant said:

> I do not approach my relatives not only because they stigmatize me. But I feel inferiority when I stay with them. I also think that they do not like me. I feel that they approach me because they do not want to disappoint me. I also do not shake their hands freely. For example, I like to kiss kids, but I am afraid of doing it. I kiss them either on their heads or on their hands. I always feel that I may transmit the disease to them though I know that HIV can not be transmitted through physical contact. (Hiwot, Age 38)

***Socio-cultural Pressures on Women***

Qualitative data shows that women with HIV/AIDS face various pressures from neighbors and relatives up on the death of their husbands. For many, death of the husbands (who are bread winners) implies social and economic hardship. Participants informed that women are more likely to be considered as causes of the death of their husbands by relatives and neighbors. The following words from participants in the interview demonstrate this fact.

> My husband was a wage earner. His income was not enough to sustain our lives. He got life tiresome and joined the army during the Eritrea war [Ethio-Eritrean war] leaving me pregnant. When he came back home, we started to live together as usual. I knew my positive status when I was pregnant of our second son who died two years ago. When he found out that I am HIV positive, he said nothing. Because he knew that he himself brought the disease from there. Our son is free from HIV. This is a testimony for not bringing the disease on my side. But, after he died, his relatives have

> been blaming me for being a cause for his death. They say; 'While he was gone for the war, she stayed here changing men as shirts and killed him. Now he is dead and she lives with comfort'. But I know myself that I did not have any relationship with other men rather than raising our son. (Sara, Age 37)

Another participant explained the challenges she encountered following the death of her husband with AIDS as follows.

> As of the death of my husband, his families opened a war on me. They said that I killed him with *digimt* [magic]. I explained to them that he had died of AIDS. But they did not want to be convinced. Even they tried to take me to witchcraft in order to identify the real cause of the death of my husband. I am a believer of God and I refused. When they strengthened their pressure, I went to the Police and it is the policemen who helped me to stop them. I knew that their motive was to take the house which is under Kebele ownership. (Konjit, Age 29)

### 4.4 Economic Challenges

It is true that women have lower economic standing in many societies. They have limited access to resources. In many societies of Ethiopia, the rule of masculinity still prevails denying women's rights to property ownership and inheritance. It is also clear that poverty and economic constraints are the major factors that put women into risky relationships leading them to HIV infection. Moreover, women with HIV face severe economic problems. HIV is added to women who were already impoverished making their situations worse.

The economic challenges are harsher for those women who lost their husbands for AIDS. In addition to being blamed for killing their husbands, they encounter several economic problems. In our society, women are at the lower strata in education, employment and control over resources. Thus, traditionally, women in many cases are dependent on

their husband's income. They are expected to stay at home providing reproductive services and for many women, particularly for rural women, the public sphere has been far from their reaches. Those women who lost their husbands for AIDS may not have any source of income. A participant told her economic problems as follows.

> I faced lots of problems following my husband's death. He has left nothing to sustain my living. Even he was not a member of any Eddir [a burial association] and he was buried with the assistance of his friends and relatives. When he was alive, he did not allow me to approach other people and did not want me to have my own work out of home. I had started to work in a certain hairdressing house; but he forced me to leave it. When he died, I had nothing to work and was extremely starved. His pension is not still allowed to me. His coworkers told me that he had taken a lot of money as a credit from their credit association. He had done this without my consent. They even requested me to pay the credit he had taken. They said that they would not guarantee the pension if I fail to pay the credit first. Even my husband did not pay rent for this house to the kebele and there are arrears of many years which I can not pay. Tomorrow morning, the kebele officials may kick me out of this house. (Konjit, Age 29)

In the setting of stigma and discrimination, women with the virus found it difficult to get employment and earn a living. Many participants could not seek employment in private works. Private employers may fire them or may not employ them if they find WLHA's HIV status. WLHA also could be absent from work places as they face frequent illnesses which could be a reason to be kicked out.

Economic challenges highly affect the health condition of WLHA. It is true that people's economic status directly correlates with their health status. WLHA are needed to take better diet and need medical treatment. But economic challenges are the major obstacles for accessing these needs. Particularly those who have started to take the ART are required

to take better diet. Those who have lower economic status could not fulfill this.

A number of participants reported that they reached the stage in which they have to take anti-retroviral therapy (ART). But because of economic constraints, some of the participants have shown little interests of taking it. They argue that ART increases appetite and they can not afford the expense of buying extra food. They also argue that if they start to take the ART and fail to get appropriate diet, they would be forced to interrupt it. This in turn may result from severe consequences on their health conditions. In addition to economic problems, there are social-cultural and religious factors that discourage WLHA from taking the ART. Some participants indicated that they found the ART confronting to their religious beliefs. An old woman participant said:

> "I do not need to take the so called life prolonging medicine [ART]. I heard that it needs food. I do not want to bother my children asking them to buy extra food for me. I also heard that it has to be taken at down and at dusk. But I always fast until 3 PM. I do not want to disappoint the Holy savior as I am going to the grave." (Zerfe, Age 55)

The Amharic name given to the ART (*ye'edme marazemia medhanit*_life prolonging drug) has made some of the participants to give a separate status for the drug. The naming has led some WLWHA to think that it confronts with their religious beliefs. The following argument from a woman participant can explain this.

> I won't need it [the ART]. People say that it prolongs life. I am a Christian, believer of God and it is only He who can prolong or shorten life. I do not want to challenge the authority of my creator. I only attend my Tsebel (holy water) at Entoto. (Getenesh, Age 40)

Economic problems are the major sources of stress and discomfort for many of the participants. Economic constraints may force women with HIV to engage in risky relationships which leads to the further spreading of HIV. Participants reported that those women who are living with HIV/AIDS and have limited economic opportunities are forced to engage in commercial sex work. In the society where women could not negotiate safe sex and with limited knowledge of how to protect oneself, it is possible to imagine the risk. Those women who have children in particular take responsibility of feeding their children and engage in risky relationship due to economic constraints. A discussant said:

> Sometimes, when I face serious financial problems, I say to myself 'why not I do business?' Living has become challenging. When I have nothing to feed my children, it might be a must to look for a man and to sleep with him. There is a friend of mine who gets wheat from the organization [PCSA]. She used to work in bar. She resigned it when she started to get the assistance. But she has no money to pay for house rent and to cook the food aid she receives. So she resumed commercial sex work. Even she asked me to work together in the same bar. To tell you the truth, I can not say to her to stop this work since I have nothing to give her. She is still working. She does not look like an HIV patient. Before she started her work, I and my friends used to support her with some money to pay for house rent. But we could not continue that. I said to her; please at least use condom. Having sex it self is very threatening for her own health condition. (Atsede, Age 31)

Another participant tells her sufferings as well as experience in her long time work as a commercial sex worker. She had known her HIV status before six years. She had worked as a commercial sex worker for about five years until she was almost in the bed.

> When I was told that I have AIDS, I did not believe it. Because I thought that it would kill me immediately if I had AIDS. I continued my work [sex work]. But I always used condom. It was only with one person that I used to go

> without condom. This is because he had been with me since I started this work and I trusted him much that he won't go to other women. (Emebet, Age 30)

The same woman tells the challenges she had faced when her sister, who had also been a commercial sex worker, caught HIV and fell sick as follows.

> When she got sick, I brought her to my home and I used to work [sex work] putting her under the bed. I had no choice. I used to take care of her and feed her four children with the money that I used to get from my customers. And, she had to tolerate falling sick under the bed while I was working on it. When she died, her funeral was celebrated like a good person, like a rich, like a married lady with respect and with all the requirements of the Church. Thanks to the Holy Savior. (Emebet, Age 30)

The woman's words tell the severity of economic problems and the stigma against people living with HIV/AIDS and commercial sex workers. Commercial sex workers who are living with HIV are more likely to face multiple stigma. They are stigmatized for being commercial sex workers as they are seen as vectors of HIV. They are also stigmatized for having HIV/AIDS.

FGD participants prioritized economic problems than socio-cultural challenges to affect them severely. As WLHA stayed longer with HIV, they have adapted better strategies of living with the virus and coping with stressful conditions and socio-cultural challenges. But they found it difficult to cope up with economic challenges. In fact, economic status and socio-cultural problems are closely interrelated. That is, women with better economic status have higher capability of coping with socio-cultural challenges. They also face little pressure from partners or family members compared to women who are economically dependent on their partners. At the same time, socio-cultural problems can result from

economic problems. For instance, stigma and discrimination against PLWHA can result from lose of livelihood and economic crisis. A discussant argued:

> Economic problems are our major worries. It is very difficult even for those who are healthy, late alone HIV patients, to cope up with economic problems. We can tolerate gossips or any other pressures from neighbors and friends. But if we have nothing to eat, how can we cope up with living? (Zinash, Age 38)

It is visible that economic constraints have their own roles to play in increasing the infection rates directly or indirectly. It is true that men from different age groups visit commercial sex workers. In a patriarchal society like ours, women (including commercial sex workers and house wives) could not negotiate for safer sex. A discussant argued:

> Particularly those women who have children have serious problems. If you are sick and want to take rest in the bed, your children won't allow you to do so asking something to eat. If you want to kill yourself, your children would come in your mind and you can not do it. Especially those who take the ART are in a problem. They must take enough food. When you want to eat some food, you will be worried about your children and you will give all you have to them. (Zinash, Age 38)

Women's lack of economic resources and their very dependence have made it difficult to minimize the spread of the virus. Thus participants argued that they need to have their own constant work in order to cope up with economic problems.

### 4.5 Coping Strategies

It is true that people living with HIV/AIDS face socio-cultural, economic and emotional challenges. For many, living with HIV/AIDS is threatening. Many encounter impoverishment, loss of employment and

livelihood, rejection, isolation, hopelessness, etc. Women in particular are subjected to such challenges. Literature shows that women are more subjected to stigma than men due to power imbalances and socio-economic inequalities (Johnson, 2002). Many face emotional and physical violence from family members or sexual partners. To cope up with such challenges, women living with HIV/AIDS employ a variety of strategies. Some of the strategies are discussed as follows.

***Tsebel (Holy Water)***

One way in which most women employ to cope up with stressful conditions is by turning to religion and prayers. Participants reported that they visit religious sites for holy water (locally called Tsebel) and believe that it has a healing power for HIV/AIDS. Almost all participants in the interview believed that (most of them are in fact believers of Orthodox Christianity) they could cure from HIV through Tsebel. But many of them informed that they do not have the financial capacity to afford the expenses of visiting Tsebel sites. Particularly those participants who have children informed that they could not visit such sites as they have responsibilities with their children. An interview participant said:

> I always think that I would have been cured if I attend Tsebel at *Entoto*. But I am poor and I can not afford the living expenses at *Entoto*. There, you need to rent a room, pay for food etc. Recently I heard that a new Tsebel has been found at Gurara around Ferensay. I want to go there. (Sara, Age 37)

Those who tried it explained their failure in terms of their own fault and thus blame themselves. A participant said:

> I confessed all my sins to my confession father. I preferred to tell the truth than going to damnation. It was after my confession that I got relief from stress. My confession father recommended me to attend Tsebel at Entoto. I did it hoping

> that I would be cured. But this did not happen because God has already labeled me as a cruel person for bothering my mother since childhood and for catching HIV through my own fault. (Tirfie, Age 27)

Quantitative data show that the majority of women living with HIV/AIDS use Holy water. The majority of the respondents (87%) are Orthodox Christians. And, 79.7% percent of the respondents answered that they drink Holy water. Participants in the interviews and FGDs argued that, although they fail to attend Holy water regularly at sites like Entoto and Shenkora, they attend it at nearby Churches. Three of the interview participants informed that they had completely lost their minds having discovered their HIV status and having faced stigma. So, according to them, though the Tsebel did not cure them from HIV, they were able to recover from mental illnesses. A participant said:

> I do not have good families. They separated all the things that I use at home. Even they put symbols on eating utensils with nail polishes so that anyone can identify them. My eating utensils are tied together and are placed in a separate area. These things angered me and I went mad. I did not know myself for about two months. I threw all my clothes away and walked bare on the streets. Then my friends took me to the Tsebel and I recovered. It was that time that I lost my teeth and the shape of my face. (Hanna, Age 28)

Holy water has served as a hope or a dream for some participants who have not tried it. They hope that some time in the future they would try it and would get better of their illness. But they either have not the financial capability or physical endurance or they are afraid of frustration if they fail to get a success. So Tsebel has served as an explanation of hope. Some others argue that it depends on one's own belief. A participant said that one has to be "a true believer who do not doubt its power of healing" to get a "real success".

Research findings on coping strategies in different countries have shown that PLWHA turn to religion and prayers for comfort and support (Nyblade et al., 2003). Both qualitative and quantitative data confirm this fact. A young participant said:

> When I get depressed, I would go to Church and pray there. While praying, I would go asleep in the compound of the Church. When I awaken, my stress and depression would go away. There has been no day in which I have been absent from the Church since I knew my HIV status. (Almaz, Age 27)

Quantitative data shows that most of the participants of the survey (95.1%) employ praying.

***Disclosure /Non-disclosure of One's HIV Status***

One way of coping with socio-cultural, economic and emotional challenges among many of the participants is to disclose their status to support institutions. This is in an effort to get food aid, counseling and home-based care services. But many of the participants informed that they had not yet disclosed their status to the general public for fear of stigma. This means that they employ both disclosure and non-disclosure of their HIV positive status simultaneously as a means of coping.

Focus group discussants reported that those women who receive food aid have been seen trying to hide themselves from the scene of other people whenever they take the assistance. Data from home based care givers also shows that one of the major problems they face in their work is participants' hesitation to accept frequent visits from home-based care givers. This is because WLWHA are afraid that their neighbors would either be suspicious or find out their HIV positive status, which could result from stigma and rejection.

The assistance from organizations (particularly food assistance) has helped PLHA to cope up with economic, emotional and social challenges. The assistance has also its own roles to play in minimizing stigma against PLHA coming from their families. Participants informed that their relationship with their families have been improved when they secured food aid from the organizations. One participant said:

> My families used to stigmatize me severely. But when I started to get wheat and oil, they improved their treatment. I told them frankly that we better agree and share the aid that I am receiving. They are poor. Currently they are afraid that I may leave them away with the food aid and they provide me much care. (Mekdes, Age 28)

In other situations, food aid can perpetuate stigma from neighbors. That is, those who get food assistance from organizations are more likely to be labeled as "having AIDS". Thus, food assistance, though has helped the beneficiaries to better cope with various challenges, necessitated the revealing of WLHA's HIV status to neighbors and friends by then perpetuating stigma. A 58 year old participant said:

> My neighbors who had always been on my side in times of happiness and sorrow turned their faces away from me as they found out that I am getting assistance from the organization. I have not told to anyone of them that I have AIDS. But I don't care if they move away from me; it would have been good if the Holy Savior had not moved away from me. Even when I was completely on the bed, there was no neighbor who came to my home to say 'let God give you His mercy'. I myself do not need them. Let God make them taste the bitter just as he has done to me. (Wude, Age 58)

***Joining PLHA/WLHA Associations***

Joining PLHA/WLHA associations and networks is another important strategy that women with HIV/AIDS employ to cope with socio-cultural

and emotional challenges. For many, the networks are very important means of winning new friends who have similar problems and feelings. Many participants indicated that they were relieved from their stresses whenever they got “people like them”. A participant said:

> When I knew that I have HIV, I went crazy. That time, there was no enough counseling service like now. But later, when I contacted people like me, I recovered. That time on, if I have heard that there is a woman with HIV, I would look for her. This is because I do not want her to face suffering like what I had faced. I would go to her home and tell her that it is possible to live with HIV. I would share to her all my experiences in order to help her get better. You know, we look for each other, share our feelings and the ways of living with HIV/AIDS. (Mekdes, Age 28)

The statements of the woman elaborate that participation in PLHA networks is an important way of learning coping strategies and productive ways of living with HIV/AIDS. In the context of stigma and socio-cultural challenges, women with HIV have found networking very crucial.

PLHA/ WLHA networks, in addition to serving as ways of learning coping strategies, are important ways of involving those who live with HIV in prevention and control efforts. Participants in the group discussions indicated that they discuss the ways of transmission of HIV and how to protect others from infection through their networks. One participant said:

> Whenever we get together, we swear in the name of God not to infect others with the disease. We always say among ourselves that our lives in this world are not good and let us protect others and make the afterlife better than this. God likes us whenever we protect his creatures from HIV. He [God] brought to us HIV and we have to tolerate this. What if he has prepared good things in the afterlife considering our suffering on this land? (Mekdes, Age 28)

Literature on coping strategies has shown that some PLHA directly cope stigma by disclosing their HIV status and by playing active roles in the prevention and control efforts. But there is only one participant who publicly disclosed her HIV status and tried to challenge stigma directly as far as this study is concerned. Most of the participants employ disclosure and denial to different bodies at the same time. They are still sensitive about other people's opinions and pressures.

Research findings have also shown that PLHA, in on effort to cope up with stigma, move to new places where their status is not known (see Nyblade et al., 2003). But this may be true either for those who have high level of income and for those who are not married. Women with low level of income could not do this. Particularly poor women who have children could not have the financial capacity of moving to new places.

Some participants reported that they always hope for a better future. They hope that medical treatment would be discovered in the future for HIV. Some of them believed that the ART is the preliminary for the discovery of the "true cure" for HIV. Such hopes serve as a way of coping. The following table shows a variety of coping strategies that participants of the survey employ.

**Table 7. Coping Strategies of the Participants of the Survey**

| Item | Answer | Frequency | Percent |
|---|---|---|---|
| **Visiting counseling centers** | Yes | 163 | 89.1 |
| | No | 20 | 10.9 |
| | Total | 183* | 100.0 |
| **Praying** | Yes | 173 | 94 |
| | No | 11 | 6 |
| | Total | 184 | 100.0 |
| **Feeding well** | Yes | 159 | 86.4 |
| | No | 25 | 13.6 |
| | Total | 184 | 100.0 |
| **Seeking emotional support** | Yes | 145 | 78.8 |
| | No | 39 | 21.2 |
| | Total | 184 | 100.0 |
| **Practicing physical exercise** | Yes | 114 | 62 |
| | No | 67 | 38 |
| | Total | 184 | 100.0 |
| **Not to worry** | Yes | 173 | 94.5 |
| | No | 9 | 4.9 |
| | Total | 183* | 100.0 |
| **Taking antiretroviral drugs** | Yes | 152 | 83.1 |
| | No | 31 | 16.9 |
| | Total | 183* | 100.0 |
| **Drinking Holy water** | Yes | 144 | 79.1 |
| | No | 38 | 20.9 |
| | Total | 182* | 100.0 |
| **Accepting the fact that you are HIV positive** | Yes | 170 | 92.9 |
| | No | 13 | 7.1 |
| | Total | 183* | 100.0 |
| **Concentrating on other activities to re-direct attention from stress** | Yes | 161 | 88.0 |
| | No | 22 | 12.0 |
| | Total | 183* | 100.0 |
| **Listening to music** | Yes | 138 | 75.0 |
| | No | 46 | 25.0 |
| | Total | 184 | 100.0 |
| **Sleeping** | Yes | 133 | 72.3 |
| | No | 50 | 27.2 |
| | Total | 184 | 100.0 |

* *Missing one or two responses*

## 4.6 Critical Needs of Women living with HIV/AIDS

This section deals with assessing the priority needs of women living with HIV/AIDS. In the prior sections, the problems that influence WLHA and the varieties of coping strategies are discussed. In this section, the critical needs that women want in order to better cope up with the challenges are discussed.

A study conducted by Family Health International (2002) grouped the needs of PLHA in to four major categories; emotional and psychological, physical, economic and health care. As far as this study is concerned, participants asserted that physical and economic needs are their priorities. That is, private house to live in and employment opportunities are identified as their priority needs. Women living with HIV/AIDS need private house as they face stigma form private house renters as well as family members. In the context of stigma, women with the virus face expulsion from rental houses or from parents' house. The survey result indicated that only 6.5 percent of the respondents had their own houses. Seventy percent of the respondents in the survey live in rented houses, 16.6 percent were still living with their parents. 6.5 percent live sharing with other people. Thus, housing is a major problem for WLHA and they always put it as their first priority need. A participant said:

> My parents are cruel. They always nag me for every simple thing. If I had my own house, I would have left them away and lead a peaceful life. I also want someone to take my children for schooling. Who is going to take care of them as of my death? (Hanna, Age 28)

Data from the survey also supports this fact. Eighty one percent of the respondents answered that they have high need of private houses. Only 5.4 percent responded that they had low demands of private housing. The rest (13.6 percent) have shown medium demands. Table 9 shows WLWHA's basic needs. The following table shows coping strategies of participants.

**Table 8. Critical Needs of Participants**

| Item | Answer | Frequency | Percent |
|---|---|---|---|
| **Emotional support** | High | 142 | 77.2 |
| | Medium | 37 | 20.1 |
| | Low | 5 | 2.7 |
| | Total | 184 | 100.0 |
| **Social acceptance** | High | 137 | 74.9 |
| | Medium | 40 | 21.9 |
| | Low | 6 | 3.3 |
| | Total | 183* | 100.0 |
| **Increased access to healthcare services** | High | 167 | 90.8 |
| | Medium | 13 | 7.1 |
| | Low | 4 | 2.2 |
| | Total | 184 | 100.0 |
| **Better nutrition** | High | 149 | 81.0 |
| | Medium | 24 | 13.0 |
| | Low | 11 | 6.0 |
| | Total | 184 | 100.0 |
| **Private house to live in** | High | 149 | 81.0 |
| | Medium | 25 | 13.6 |
| | Low | 10 | 5.4 |
| | Total | 184 | 100.0 |
| **Home based care services** | High | 130 | 71.0 |
| | Medium | 41 | 22.4 |
| | Low | 12 | 6.6 |
| | Total | 183* | 100.0 |
| **Financial assistance** | High | 148 | 81.3 |
| | Medium | 23 | 12.6 |
| | Low | 11 | 6.0 |
| | Total | 182* | 100.0 |
| **Counseling services** | High | 149 | 81.0 |
| | Medium | 31 | 16.8 |
| | Low | 3 | 1.6 |
| | Total | 184 | 100.0 |
| **Job opportunities** | High | 153 | 83.2 |
| | Medium | 17 | 9.2 |
| | Low | 14 | 7.6 |
| | Total | 184 | 100.0 |
| **Support for your children** | High | 121 | 65.8 |
| | Medium | 27 | 14.7 |
| | Low | 36 | 19.5 |
| | Total | 184 | 100.0 |

** Missing one or two responses*

The other priority need of women with HIV/AIDS is employment opportunity. The survey result indicates that 83.2 percent of the participants highly need job opportunities (see table 9). As shown before, most of the participants are poor. The survey result indicates that 93.4 percent of the participants had no formal employments. From among participants who had no formal employment, 48.8 percent are casual workers (wage earners), 43.0 percent housewives and 4.1 percent pensioners. Only 6.6 percent of the participants of the survey have been employed formally. Among these, 16.7 percent earn salaries ranging form 401-800 birr. Only 8.3 percent responded that they earn above 801 birr. The remaining (75 percent) earn salaries between 201-400 birr. This shows that women with HIV are in a severe problems and lack employment opportunities. Most of them have survived on the assistance they receive from the NGOs. To this effect economic needs and employment opportunities are given a priority.

Participants in the qualitative study reported that they require private employments (i.e. employing themselves). This is for two reasons. One is that most of them have no education and they can seek formal employments. The survey result indicates that only 1.6% of the participants have education at college level, 27.2 percent have secondary, 38.6 percent have primary schooling and (9.2) people can read and write. The remaining (23.5 percent) are illiterate. Thus, with the given level of education, it is very difficult for the majority of the respondents to seek formal employments. They can not engage in employments that are done manually as they do not conform to their health situations.

Second, participants in the interviews as well as group discussions indicated that they face stigma and discrimination from employers. Particularly private employers could have limited interests to employ PLHA if they are aware of PLHA's HIV status. Even if they do not know it,

they may fire PLHA as PLHA could not consistently present at their work places due to frequent illnesses. Thus, most of the participants need their own private works. A discussant said:

> It is difficult for those us to work in private houses. Even if we seek to work in private works because of economic problems, the employers would stigmatize us. Therefore we need our own works which we do it whenever we feel good and leave it whenever we feel sick. (Meseret, Age 28)

The participants in the qualitative study receive assistance from the NGOs. The assistance includes 45 kilograms of wheat, three liters of food oil, and three kilograms of lentils. However, they still are at high need for financial support. Many participants indicated that they need financial assistance to cover the expense of house rent and buy firewood or fuel for cooking. The survey result supports this fact. That is, 81.3 percent of the participants responded that they are at high demand of financial assistance (See table 9). Group discussants also explained that thought many WLHA around Arat Kilo receive food assistance, they are still suffering from financial constraints. Some of them have been forced to engage in commercial sex work to cover the expenses of house rent and other expenses. A discussant said:

> There is a friend of mine who gets wheat and oil from the organization. She has rented a house in front of mine. She has a child. She was a commercial sex worker before she secured the assistance. But when she has nothing to pay for the rent, she resumed commercial sex work. One Saturday, I purposefully stayed at my home working handicraft and looked her through the window of my house. To tell you the truth, I counted a total of eleven men getting in and coming out of her house from 10 am to 6 pm. Sex is dangerous for the health condition of those who live with HIV/AIDS, particularly for women. When I explained this to her she said; 'I do not want to die in starvation'. (Gennet, Age 36)

Most of the participants indicated that the assistance they receive from the NGOs is not enough. Particularly women who have children reported that they should be supplemented with additional assistance from organizations. Moreover, they informed that they had always been worried about the sustainability of the assistance. They felt that the NGOs may quit their assistance anytime they want. It is not without any reason that they were worried. At first, the assistance was given to people who had tuberculoses. Then the NGOs provided their assistance only to those people who have HIV/AIDS and they requested people who used to get assistance for a blood test. Those who had HIV/AIDS have secured assistance. Those who had not and still suffering from tuberculosis where rejected. A 58 year woman participants informed how she secured the assistance as follows.

> At first, I used to get assistance because I had TB. Later they said that they would no longer give assistance for TB patients. They wanted to give assistance only to those people who caught AIDS. So they asked me to undertake HIV test. I was then afraid that my children would die in hunger if I had been free from AIDS. I gave my blood for test and they told me I have AIDS. This way I secured the assistance, Thanks to the Holy Savior. (Wude, Age 58)

Participants also reported that the NGOs are threatening them that the assistance will only be provided for those who have developed AIDS and who started to take the ART. This is also the reason behind the high need for private employments among the majority of the participants. The survey result indicates that 83.2 percent of the participants highly need employment opportunities.

There is no doubt that the support assisted the participants to better cope up with life with HIV/AIDS. Participants in the interview and group discussions informed that their lives were almost in danger if they had

not been supported with food. The survey result indicates that the those participants who receive the assistance found it very helpful in for example having better coping ability, better emotional status, better hope for the future and in creating better efficiency at work. What most participants doubt was the quality, quantity and sustainability of the assistance. One interview participant said:

> If I have not been getting assistance from the organization, I would have been a beggar. It means a lot for me. But, I am always worried about its continuity. Moreover, it is not good to always depend on others' help. They better give us permanent works. We can work like other healthy people. The support also is not enough. For example people who have children and those who do not have are given equal amount of support. This is not fair. (Getenesh, Age 40)

The majority of the participants in the qualitative study shared the idea of this woman. They indicated that they found dependence on support psychologically threatening. Some participants informed that they are forced to label themselves as idle and burden for others. Some participants informed that they need employment not only for economic reasons, but also for their emotional and psychological betterment. One participant in the interview informed:

> I want to have my own work. The CCF organized us and provided us training on small-scale businesses. But we have not started work. Currently I want to have my own work. If this is not possible, I need to get employment outside of my home. I do not want to spend my time sitting idle in my home. I like to communicate with people. When I sit idle, I start to think about the disease and death which highly stresses me. For example, I like works like waitering in which I communicate with people. (Emebet, Age 30)

Many of the participants are highly critical about the type of assistance they receive. Most of the participants indicated that it would have been good if they can be provided with Teff (staple crop in Ethiopia) instead of wheat. A participant said:

> The organization gives us 45 kilos of wheat, 3 litters of oil and 3 kilos of lentils. But this is not enough as we can not always eat wheat. We can not make it Enjera [staple food for most Ethiopians]. It is boring to always eat bread, Nifro [cooked wheat] or Kolo [roasted wheat]. If I had some income, I would have buy some kilos of Teff and mix it with the wheat for making Enjera. We can not sell the wheat and buy Teff instead. They have forbidden us… It would have been best if they can give us 25 kilo of Teff instead of 45 kilo of wheat. Even when I feel sick, I beg my daughters to buy Enjera for me. My son, no one can hate his mother and Teff's Enjera. (Zerfie, Age 55)

Many participants asserted that they need better diet in order to cope up with HIV/AIDS. Particularly those who take the ART are expected to take better diet. However, such needs are not still addressed.

Participants also reported that they need social acceptance and emotional support. The survey result indicates that 77.2 percent of the participants were at high need of emotional support. Also the majority of the participants (74.9 percent) responded that they highly need social acceptance. Counseling services are also mentioned as priority needs by 81 percent of the respondents.

The other major problem that most women are highly worried about is the future of their children. They need someone to care for their children. The survey result has shown that the majority of the participants (66.1 percent) have one or more children and most of them responded that they are at high need of support for their children.

The other crucial need of WLHA is provision of appropriate healthcare services. The survey result indicates that 90.8 percent of the participants are at high need of increased access to healthcare services. Currently, the trend of healthcare provision for PLHA is directed towards treating them at their own homes. The purpose of provision of home-based care services is to minimize the crowding of hospital beds and to enable patients receive appropriate assistance “without suffering”. But the quality of care provision is questioned by most of the participants and home-based care givers themselves. Home-based care givers informed that they do not think that they are sufficiently trained. They also indicated that many times they face shortage or delay of material supply from the NGOs.

Participants were asked to compare and contrast the needs mentioned above. Most of them agreed that economic needs are their top priorities. Some of the participants in the group discussions said; "we have enough knowledge of HIV/AIDS and how to live with it. We ourselves can counsel others. It is the newly infected who need counseling". It seems that those women who knew their status recently are at high need of counseling services compared to those who lived with HIV for long periods of time. Thus, most participants need to have their own sources of income. This is very crucial as economic dependence is a major source for stigma, limited access to healthcare services and other problems.

### 4.7 Roles of Women Living with HIV/AIDS in the Prevention and Control Efforts

Literature on people living with HIV/AIDS has shown that the participation of PLWHA in the prevention and control programs is crucial in bringing about significant changes (UNAIDS, 1999). Thus, women

living with HIV/AIDS could play a variety of roles in the prevention and control efforts.

The roles of WLHA in the prevention of HIV/AIDS can be classified in to two categories; private and public roles. The private roles of WLHA include their efforts to protect family members and others from HIV infection. This incorporates disclosing their HIV status to family members and undertaking cautions in sharing sharp materials, tooth brushing and other tools through which blood contamination is more likely. The other private role of WLHA can be the prevention of mother to child transmission. This includes undertaking protections before and after child delivery. WLHA also can play significant roles in the prevention and control efforts by distancing themselves from risky relationships with others. Many participants in the qualitative study informed that they disclosed their HIV status to men who sought sexual relationships with them. A participant said:

> Once, I was traveling from Addisu Gebeya to Giorgios by bus. A man sat down on my side sharing a bench. We exchanged some words. When I got down from the bus, he did too and followed me from the back. Then he approached me and held my hands. He asked me to stay for some time with him. I said nothing but opened my bag and showed him my Tesfa Goh [a PLWHA association] ID. He said nothing but run away until his legs carried him. You see, if you dress well, people do not think that you may have HIV. Some people do not believe you even if you tell them that you have HIV. They have to see you in the bed. (Tirfie, Age 27)

Many participants indicated that they have big responsibilities in protecting others form HIV infection. They indicated that it is morally and religiously unacceptable to stay ignorant about protecting others. Young women with HIV reported that they face a threat of physical violence from men for refusing men's desire for sexual partnership. They

have found it immoral to engage in sexual relations being aware of their HIV positive status. They also find it difficult to disclose their status to the people who seek such kind of relationships for fear of stigma. A young discussant said:

> Young men in our surrounding request me for sexual relations. They do not know my status. But I do not like to do it. Even today, while I was coming to you, a certain young man stopped me on the way and held my hands tightly. He asked me as usual. But I refused. Then he slapped me and went away. [What if you tell him your status?] I won't tell him. I told you that I am living sharing a small room with my friend. I do not pay her. And, if I tell my HIV status to this person, he may tell to any one in the area and if my friend discovers this, she would certainly kick me out within an over night. I choose to carry his beatings rather. Sometimes, when men raise such requests, I say to them 'what if I have HIV?' One young man said; 'do you think I am a foolish person who could not identify those who have HIV and those who have not?' (Seble, Age 23)

The public roles of WLHA include disclosing their HIV status to the general public and undertaking a wide range of participation in awareness creation among neighbors and communities. Qualitative data shows that some WLHA play active roles by being members of WLHA/PLHA associations and by creating their own networks. Some participants reported that they participate in "peer education" programs and they share ideas among themselves. They also play roles by sharing coping strategies and productive ways of living with HIV/AIDS among themselves. Some participants are involved in community service programs and provide home-based care services for those who have developed AIDS. However, both qualitative and quantitative data show that a small proportion of the participants were taking part in the public roles compared to their roles in the private sphere. Quantitative data shows that only 20.7 percent of the participants are taking part in the

public roles. Table 10 shows women's roles in the prevention and control efforts in the public sphere.

**Table 9. Roles of Participants in HIV Prevention Programs**

| Item | Answer | Frequency | Percent |
|---|---|---|---|
| **Do you participate in anti-HIV campaigns?** | Yes | 38 | 20.7 |
| | No | 146 | 79.3 |
| | Total | 184 | 100.0 |
| **Being member of PLHA/WLHA associations** | Yes | 24 | 63.2 |
| | No | 15 | 6.8 |
| | Total | 38* | 100.0 |
| **Awareness creation programs** | Yes | 25 | 64.1 |
| | No | 14 | 35.9 |
| | Total | 38* | 100.0 |
| **Providing care and support for those who need it** | Yes | 28 | 73.0 |
| | No | 10 | 27.0 |
| | Total | 38* | 100.0 |
| **Emotional support by sharing your experience** | Yes | 36 | 92.2 |
| | No | 2 | 7.8 |
| | Total | 38* | 100.0 |

**Those participants who responded affirmatively for the first item*

There are a variety of reasons behind the limited participation of women in the prevention and control efforts in the public sphere. One important reason is the participants' fear and/or bad experience of stigma and discrimination. Many participants indicated that they have high interests of participating in the prevention efforts but are afraid of the consequences of public disclosure. A participant said:

> There was a friend of mine who had HIV. He started to teach about AIDS in schools and public places. As people found that he had HIV, they stigmatized him. House renters chased

> him out of home… No one was approaching him. Then he lost his mind in anger and facilitated his death. He was not that much damaged by the virus. Even he had not started the ART. This is a big lesson for me. (Kuri, Age 25)

The other factor that has affected women's roles is the fact that women have responsibilities at home. Women are subjected to household chores. So, most of them may not have extra time to spend in the programs. Furthermore; participants reported that they have pressures from their husbands and they have to get the full consent of their husbands. A participant indicated her husband's response when she asked him to disclose her HIV status to the public as follows.

> 'You went here and there and brought HIV to me. Is that not enough? How dare you do this? Do you want me to lose somebody to burry my body when I die? Do you know what people will say when you tell them that you have AIDS? They will certainly blame me for bringing the disease to you. They do not understand the truth.' Then he went on pulling a stick against me. I even face problems when I want to go to participate in the community communication. I have to ask his permission. (Zinash, Age 38)

The other factor that deterred women from active participation in the prevention programs is lack of information and knowledge on how to go about it. Poor health conditions and limited access to healthcare services are also some of the obstacles.

# 5. SUMMARY AND CONCLUSION

## 5.1 Summary

The study has focused on the factors that make women more vulnerable to HIV infection, socio-cultural and economic challenges encountering women living with HIV/AIDS, the strategies they employ to cope up with such challenges, their basic needs and their roles in the prevention and control of HIV/AIDS.

Poverty, in association with other socio-cultural factors, is identified as one of the major factors that put women into risky relationships. Poverty and economic dependence of women are added to gender-based power differences denying them the right to negotiate safe sex. Poverty also exacerbates rural-urban migration in combination with socio-cultural pressures on young women putting them into high risk. Poverty is also a factor that denies women from accessing appropriate healthcare services which could also increase their vulnerability. Poor women are also more likely to face sexual violence that may result from HIV infection.

Women living with HIV/AIDS are subjected to socio-cultural pressures at different settings; at home, at workplaces and in the society. Stigma and discrimination and pressures from partners or husbands are identified as the major problems. Women living with HIV/AIDS and those people who are connected to them are subjected to stigma and discrimination. There have been in fact improvements in the way WLHA have been treated at home and in the society. However, still women with HIV/AIDS are more likely to be blamed and stigmatized.

Stigma and discrimination have profound effects on the prevention and control efforts. Stigma discourages those who live with the virus from

disclosing their status to the general public and to play active roles in the prevention and control efforts. It has also impended WLHA from seeking and accessing healthcare services including home-based care services. Stigma and discrimination have also put those who live with the virus in to severe economic problems as they fond it difficult to secure employment opportunities.

The study has also shown that women living with HIV/AIDS encounter severe economic problems. The problems are more severe among those women who lost their husbands to AIDS and among those who have children. The economic problems emanate from the very dependence of women on the income of their husbands and gender inequality in access to economic resources. It also emerges from socio-cultural pressures under which women are unable to earn a living. In the context of stigma and discrimination, women could not secure employments. Their health conditions also may not allow them to work regularly in employments which require physical labor. Even those women who get assistance from the NGOs reported that the assistance is not enough and their economic needs are not still addressed.

Economic problems in turn have resulted from negative consequences on the prevention and control efforts as some are forced to engage in risky relationships to cope up with economic challenges. Economic problems have also discouraged WLHA from taking the ART. This is because they are needed to take better diet and those who can not afford this prefer not to start to take it.

To cope up with socio-cultural, economic and emotional challenges, WLHA employ a variety of strategies. To cope with stressful conditions, a majority of the participants visit religious sites for Holy waters and they turn to religion and prayers. Most of them have the belief that Holy

waters have healing powers and those who tried it and failed to get success explain their failure in terms of their own fault. The participants also employ disclosure and denial of HIV status at the same time in order to cope up with socio-cultural and economic challenges. They disclose their status to support institutions and PLHA/WLHA associations in order to secure economic and emotional assistance. At the same time, they hide their status to neighbors and even family members in order to cope up with stigma and discrimination. Some participants cope up against stigma by accepting the fact that they are HIV positive and by disclosing their status to the general public by then taking active roles in the prevention and control efforts.

The major needs of the participants include economic needs (financial assistance, employment opportunities etc), healthcare needs (increased access to healthcare services and home-based care services), housing, food aid, support for their children, social acceptance, counseling services and emotional support. The participants stressed that economic needs and housing are the priority needs. Housing is crucial as the participants face sigma and discrimination from renters. Economic needs are expected to avoid women's dependency on assistance.

The roles of women in the prevention and control of HIV/AIDS range from protecting others by implementing precautions to a wide range of participation in awareness creation programs. They play roles in sharing coping strategies and providing emotional support to others who are newly diagnosed. They play significant roles in the prevention of mother to child transmission. Some participants play active roles by being members of PLHA/WLHA associations. Some others have been playing active roles in provision of home-based care services for those who developed AIDS. However, most of them have not disclosed their status to the general public and have played limited roles in the awareness

creation programs for various reasons. The reasons include stigma and discrimination, pressures from husbands or sexual partners, household burdens, and limited knowledge on how to participate in the prevention efforts.

## 5.2 Conclusion

The problem of HIV/AIDS in women is highly complicated. The factors that contribute to women's vulnerability to HIV are complex and intertwined with each other. They are intertwined with the existing socio-cultural and economic situations, gender relations and generally the status of women in decision making in the social, economic and political lives. The socio-economic and cultural diversities among women in Addis Ababa has made it difficult to draw a clear cut conclusion and generalization on the factors that contribute to women's vulnerability as well as the problems that women living with HIV/AIDS are encountering. The problem needs an in-depth cross-sectional study to explore how differences in socio-economic status affect the women's experiences with HIV/AIDS.

In general, this specific study has found that women living with HIV/AIDS in Arada Sub-city are more likely to encounter serious socio-cultural, economic, and emotional challenges. They are more likely to face blame, stigma and discrimination, and violence from husbands (if are married). Women living with HIV/AIDS employ a variety of coping strategies to deal with emotional, socio-cultural and economic challenges. The strategies they employ include disclosing their HIV status to support institutions, hiding it to family members and neighbors, turning to religion and visiting religious sites for holy waters. Joining PLHA/WLHA associations and creating their own networks are some of the strategies employed by most of the participants. Their critical

needs include financial assistance, employment opportunities, increased access to healthcare services, private house to live in, and support for their children. Women living with HIV/AIDS play significant roles in the prevention and control efforts. Their roles range from private (protecting others from infection, prevention of mother to child transmission etc) to public (disclosing their status to the general public and participating in awareness creation programs and provision of home-based care services for those who are in need).

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## Appendix I

## Interview Guide

## Questions Addressed to Women Living with HIV/AIDS

This interview is prepared to gather data and information on the problems affecting women living with HIV/AIDS. Participation in this interview is voluntary and your honest participation will greatly assist in meeting the goals of this study as it is only you who know about your feelings and situations you have gone through. The information you provide will be kept strictly confidential. Thus, you are kindly requested to give your frank response.

Thank You!!

1. Please give a brief personal biography (age, place of birth, residence, marital status, religion, level of income…)

   _____

2. What problems have you encountered after you found that you are HIV positive (social, and economic problems, reaction from family members, friends, coworkers)

   _____

3. What do you think are the factors that exposed you to HIV?

   _____

4. How do you view your life before and after you have known your HIV positive status? (social participation, emotional status, economic situations…)

   _____

5. What is your experience concerning stigma and discrimination?

   _____

6. How do you cope up with the problems you encounter? What are your strategies?

   _____

7. Do you currently receive assistance from organizations? What kind of assistance is it? How does the assistance affect your situations?

_____

8. What are your critical needs?

_____

9. Do you participate in anti HIV/AIDS campaigns?

_____

10. What could be the role of the government, non- government organizations and different institutions in minimizing the problems of people with HIV/AIDS?

_____

## Appendix II

## Focus Group Discussion Guide

## Questions Addressed to Women Living with HIV/AIDS

This discussion is prepared to gather data on the problems that are affecting women living with HIV/AIDS. Participation in this interview is voluntary and your honest participation will greatly assist in meeting the goals of this study. The information you provide will be kept strictly confidential. Thus, you are kindly requested to give your frank response.

Thank You!!

1. What are the factors that make women vulnerable to HIV infection?

   _____

2. What are the problems faced by women living with HIV/AIDS?

   _____

3. What strategies do women living with HIV/AIDS employ to cope up with HIV/AIDS?

   _____

4. What are the critical needs of women living with HIV/AIDS?

   _____

5. What could be the roles of women living with HIV/AIDS in the prevention and control of HIV/AIDS?

   _____

6. What roles could government and non-government organizations play to minimize the problems faced by people living with HIV/AIDS?

   _____

**Appendix III**

**Interview Guide**

**Questions Addressed to Staff Members of PCSA and HAPCSO**

This interview is prepared to gather data and information on the problems that are affecting women living with HIV/AIDS. Participation in this interview is voluntary and your honest participation will greatly assist in meeting the goals of this study. The information you provide will be kept strictly confidential. Thus, you are kindly requested to give your frank response.

Thank You!!

1. What is your position in the organization?

   _____

2. What are the major services of the organization?

   _____

3. What are your organization's major target groups? How do you select them?

   _____

4. Does your organization consider gender differences in the selection of beneficiaries? Why?

   _____

5. How does your organization ensure that the services are reaching the target groups appropriately?

   _____

6. What are the critical needs of women with HIV/AIDS? Which ones are addressed by your organization?

   _____

7. What are the problems encountered by women who are your beneficiaries?

   _____

8. Does your organization encourage women with the virus to participate in anti-HIV /AIDS campaigns? How?

   _____

9. How do you compare your organization's services and beneficiaries' needs?

   _____

10. What problems have you encountered in your works with people with HIV/AIDS?

    _____

**Appendix IV**

**Interview Guide**

**Questions Addressed to Home-based Care Givers**

This interview is prepared to gather data on the problems that are affecting women living with HIV/AIDS. Participation in this interview is voluntary and your honest participation will greatly assist in meeting the goals of this study. The information you provide will be kept strictly confidential. Thus, you are kindly requested to give your frank response.

Thank You!!

1. Residence _____
2. Level of education_____
3. Have you got any training to give support and care to people living with HIV/AIDS? What kind of training is it?

   _____
4. What are the problems you encountered in relation to your works?

   _____
5. In your opinion is the support provided to people with HIV/AIDS enough? What aspects should be improved?

   _____
6. What are the critical needs of people living with HIV/AIDS?

   _____
7. What kind of relationship you have with people living with HIV/AIDS?

   _____

**Appendix V**

**Questionnaire**

**Addis Ababa University**

**School of Graduate Studies**

**Institute of Gender Studies**

Good morning. The purpose of this questionnaire is to study the socio-economic and cultural problems that are affecting women living with HIV/AIDS in Addis Ababa. The target population for this study is women living with HIV/AIDS. Thus, you are selected to participate in the study. Participation in this study is voluntary and everything you say will remain confidential. Your views are very important and your honest participation will greatly assist in meeting the goals of this study. Thus, you are kindly requested to give your frank response.

Thank You!

Notice;

- Do not write your name
- If you do not understand the questions, you can ask for further explanation
- The information to be obtained through this questionnaire will only be used for the survey
- Circle the number corresponding to your answer or fill in the blank spaces

**I. Respondent's Background Information**

1. Place of residence (*Kebele*) _____
2. Age 1) 15-24 2) 25-35 3) 36 and above
3. Level of education 1) illiterate 2) read and write 3) primary (1-8) 4) secondary (9-12) 5) Higher education (college)
4. Marital status 1) never married 2) currently married 3) divorced 4) widowed
5. Religion? 1) Orthodox 2) Protestant 3) Catholic 4) Muslim 5) other (specify) _____

6. Are you currently employed? 1) yes 2) no

7. If your answer for question number 6 is “yes”, how much is your average monthly income 1) 201-400 2) 401-800 3) 801 and above

8. If your answer for question 6 is “no”, your employment status is

1) Housewife 2) pensioner 3) casual worker

4) other (specify) _____

9. Do you have children? 1) Yes 2) No

10. If your answer for question 9 is "yes", how many are they?

1) one 2) two 3) three 4) four and above

11. What type of house do you live in?

1) rented from private 2) rented from *kebele* 3) private

4) parents’ house 5) sharing with other people

6) other (specify) _____

**II. Women’s Experience with HIV/AIDS**

12. When did you know your HIV status? 1) less than 6 months

2) 6 months -1 year 2) 1-2 years 3) 2-3 years

4) above 3 years

13. What factor do you believe exposed you to HIV/AIDS?

1) unprotected sexual intercourse 3) forced sex (rape)

2) blood contact 4) harmful traditional practices

5) other (specify) _____

14. Have you disclosed your HIV status? 1) Yes 2) No

15. If your answer for question number 14 is “yes”, to whom have you disclosed?

1) family members 2) co-workers 3) the society 4) confession father

5) other (specify) _____

If you disclosed your HIV positive status to your family, what problems have you encountered at home? (Multiple answers are allowed)

| | Yes | No |
|---|---|---|
| 16. Blamed for being promiscuous | 1 | 2 |
| 17.Faced emotional violence from family members | 1 | 2 |
| 18.Chased out from home | 1 | 2 |
| 19.Separation of eating utensils | 1 | 2 |
| 20.Not allowed to participate in housework | 1 | 2 |
| 21.Other (specify) _____ | | |

If you have been employed and disclosed your HIV positive status to your co-workers, what problems have you encountered at workplaces? (Multiple answers are allowed)

| | Yes | No |
|---|---|---|
| 22. Forced to resign from work | 1 | 2 |
| 23. Denied promotion | 1 | 2 |
| 24. Ostracized by workmates | 1 | 2 |
| 25. Assigned to a different responsibility where you had less contact with other people | 1 | 2 |
| 26. Other (specify) _____ | | |

If you disclosed your HIV positive status to the society, what challenges have you encountered in the society? (Multiple answers are allowed)

| | Yes | No |
|---|---|---|
| 27.Abandoned by neighbors | 1 | 2 |
| 28. Chased out from rental houses | 1 | 2 |
| 29. Denied healthcare services | 1 | 2 |
| 30. Loss of respect from the society | 1 | 2 |
| 31.Differential treatment in public places | 1 | 2 |
| 32.Other (specify) _____ | | |

In your opinion, why do you think people stigmatize or discriminate those who live with the virus? (Multiple answers are allowed)

| | Yes | No | Don't know |
|---|---|---|---|
| 33. Lack of sufficient knowledge about HIV and AIDS | 1 | 2 | 3 |
| 34. Fear of death from AIDS | 1 | 2 | 3 |
| 35. Because people with the virus are considere promiscuous | 1 | 2 | 3 |
| 36.Because HIV is considered as a curse from God | 1 | 2 | 3 |
| 37. Because people do not recognize their stigma actions | 1 | 2 | 3 |
| 38. Other (specify) _____ | | | |

If you disclosed your HIV status to support institutions, what benefits you have got? (Multiple answers are allowed)

| | Yes | No |
|---|---|---|
| 39. Increased access to healthcare services | 1 | 2 |
| 40. Economic assistance from institutions | 1 | 2 |
| 41. Opportunity to participate in anti-HIV campaigns | 1 | 2 |
| 42. Wining new friends | 1 | 2 |
| 43. Learning coping strategies | 1 | 2 |
| 44. Other(specify) _____ | 1 | 2 |
| | | |

45. Has there been an improvement in the way you have been treated by your family overtime?

1 Yes 2 No

If your answer for question 45 is "Yes", what factors do you think have brought about this change? (Multiple answers are allowed)

| | Yes | No |
|---|---|---|
| 46. Increase of awareness about the epidemic | 1 | 2 |
| 47.Effective intervention by government and non-govern organizations | 1 | 2 |
| 48. Because your income has increased from institut assistance | 1 | 2 |
| 49. Other specify _____ | | |

**III. Coping Strategies**

What strategies you have to better cope up with the virus? (Multiple answers are allowed)

| | Yes | No |
|---|---|---|
| 50. Visiting counseling centers | 1 | 2 |
| 51. Praying | 1 | 2 |
| 52. Feeding well | 1 | 2 |
| 53. Seeking emotional support from family members | 1 | 2 |
| 54. Practicing physical exercise | 1 | 2 |
| 55. Not to worry | 1 | 2 |
| 56. Taking antiretroviral drugs | 1 | 2 |
| 57. Drinking Holy water | 1 | 2 |
| 58.Accepting the fact that you are HIV positive | 1 | 2 |
| 59. Concentrating on other activities to re-direct attention stress | 1 | 2 |
| 60. Listening to music or watching television | 1 | 2 |
| 61. Sleeping | 1 | 2 |
| 62. Other specify _____ | | |

**IV. Critical Needs of Women with the Virus**

What do you think are the critical needs of women with the virus? (Multiple answers are allowed)

| | High | Medium | Low |
|---|---|---|---|
| 63. Emotional support | 1 | 2 | 3 |
| 64. Social acceptance | 1 | 2 | 3 |
| 65. Increased access to healthcare services | 1 | 2 | 3 |
| 66.Better nutrition | 1 | 2 | 3 |
| 67. Private house to live in | 1 | 2 | 3 |
| 68. Home based care services | 1 | 2 | 3 |
| 69. Financial assistance | 1 | 2 | 3 |
| 70. Counseling services | 1 | 2 | 3 |
| 71. Job opportunities | 1 | 2 | 3 |
| 72. Support for your children | 1 | 2 | 3 |
| 73. Other(specify)_____ | | | |

**V. Roles of Intervention Organizations**

74. Do you get assistance from any institution? (If your answer is "no", go to question number 80). 1) Yes 2) No

75. If your answer for question 74 is 'yes' what kind of institution is it? (Multiple answers are allowed) 1) VCT center 2) health center

3) NGO 4) GO

5) religious institution 6) other (specify) _____

76. What kind of assistance you get from the institution?

1) financial 2) counseling 3) ART 4) home based care

5) food aid 6) other (specify) _____

77. How do you evaluate this assistance? It is

1) enough 2) not enough

78. How does this assistance affect your situation?

1) increase in income 3) better coping ability

2) better emotional status 4) better health status 5) better hope for the future 6) greater efficiency at work 7) Other(specify) _____

**VI. Roles of Women with the Virus in the Campaign against HIV/AIDS**

79. Do you participate in anti-HIV campaigns? 1) Yes 2) No

If "yes", in which of the following areas you participate? (Multiple answers are allowed)

| | | Yes | No |
|---|---|---|---|
| 80 | Being member of PLWHA/WLWHA associations | 1 | 2 |
| 81 | Awareness creation program (teaching the society) | 1 | 2 |
| 82 | Providing care and support for those who need | 1 | 2 |
| 84 | Emotional support by sharing your experience as well a coping strategies | 1 | 2 |
| 85 | Other (specify) _____ | | |