

ADDIS ABABA UNIVERSITY  
SCHOOL OF GRADUATE STUDIES

THE GENDER DIMENSION OF LIVING WITH HIV TREATMENT  
DRUGS: CHALLENGES AND OPPORTUNITIES OF ANTI  
RETROVIRAL USERS AT ZEWDITU MEMORIAL HOSPITAL

BY : HERAN ABEBE

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SCHOOL OF GRADUATE STUDIES**

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**BY  
HERAN ABEBE**

**APPROVED BY BOARD OF EXAMINERS:**

\_\_\_\_\_  
**Chairman of Department  
Graduate committee**

\_\_\_\_\_  
**Signature**

\_\_\_\_\_  
**Advisor**

\_\_\_\_\_  
**Signature**

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**External Examiner**

\_\_\_\_\_  
**Signature**

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**Internal Examiner**

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**Signature**

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## **Acronyms**

AAHB

Addis Ababa Health Bureau

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti Retroviral Therapy
ARV	Anti Retro Viral
GFATM	Global Funds for HIV/AIDS, Tuberculosis and Malaria
HAART	Highly Active Antiretroviral Therapy
HAPCO	HIV/AIDS Prevention and Control Office
HIV	Human Immunodeficiency Virus
HTP	Harmful Traditional Practices
ICRW	International Center of Research on Women
IEC	Information, Education and Communication materials
MOH	Ministry of Health
NGOs	Non- governmental Organizations
OI	Opportunistic Infections
PEFAR	President Bush Emergency Plan for AIDS Relief
PEP	Post exposure prophylaxis
PMTCT	Prevention of Mother to Child transmission of HIV
PLHIV	People Living with HIV/AIDS
STD	Sexually Transmitted Diseases
UNAIDS	United Nation joint program on HIV
UNIFEM	United Nation Fund for Women
VCT	Voluntary Counseling and Testing
VSO	Voluntary Service Organization
WHO	World Health Organization

## Glossary

<i>Edir</i>	Indigenous voluntary association established primarily to provide mutual aid on burial matters but also to address other community matters ( Pankhurst & Hailmariam, 2000).
<i>Equib</i>	Traditional money saving association in which people contribute certain amount of money and receive their cumulative share turn by turn.
<i>Injera</i>	Stable food of Ethiopians mainly made of Teff but could also prepare from barely, wheat, maize and sorghum. It looks like big pan cake and eaten with different sauces.
<i>Kebele</i>	The smallest administrative unit of the local government structure in Ethiopia.
<i>Kollo</i>	A snack made of different roasted grains for example barely, wheat, peas etc.
<i>Khat</i>	Khat ( <i>Catha edulis</i> ) is an evergreen plant that grows mainly in Ethiopia, Yemen and other African countries along the coast of the Indian Ocean. Its fresh leaves are chewed or consumed as tea and acts as a stimulant ( Kebede etal., 2005).
<i>Tella</i>	A locally prepared alcoholic drink brewed from grains and yeast.
<i>Mesob</i>	A circular container where Injera is traditionally kept.

## **Abstract**

*This research mainly focused on men and women who are living with the life long HIV treatment drugs (ART). It has taken a gender lens to identify the socio-cultural and economic challenges and opportunities they encounter in an effort to fulfill the requirements associated with ART. The requirements under which participants were examined include adherence, monitoring health status, nutrition, Khat and alcohol use and safer sexual practices. In-depth interviews and focus group discussions were the major source of data collection tools and a small scale survey was also conducted.*

*Accordingly, findings revealed that poverty, fear of stigma and gender based violence influence the adherence condition of women to greater extents than men. It is also found out that women's household responsibilities and men's difficult working environment challenges their ability to monitor their health status to the level ART use require. With regard to fulfilling the nutritional requirements of ART, beyond the general limitation of access to sufficient food, gender related norms are affecting men and women differently. Men are more challenged by their inability to prepare and serve their own food while women give priorities to feed other family members.*

*The study has found out that the use of Khat and alcohol by men taking ART is at the minimal level. But rather starting ART has become the cut off point from such addictions and related risky and violent behaviors. Findings on meeting the requirements of practicing safe sex revealed that women's lack of sexual negotiation power further exposing them to re- infection and contracting drug resistant HIV strain. Regarding identified opportunities; free provision of ART, food assistance targeting poor women, financial assistance for some men in the formal sector and family acceptance and support for adherence are the major ones. In general, the study has shown that gender based differences can influence the challenges and opportunities of meeting the requirements of ART from a variety of directions.*

# 1. INTRODUCTION

## 1.1 Background

For more than two decades, HIV/AIDS has posed great challenge for our world. The existence of the virus was first identified in USA in early 1980's among homosexual men, soon after it has spreaded all over the world causing drastic social, economic and demographic crisis on humankind. The spread of the epidemic has not been halted yet, in 2007 alone an estimated 2.5 million individuals were newly infected and about 2.1 million died due to AIDS. A total of 33.5 million persons are living with the virus currently (UNAIDS, 2007).

Large variations exist in the effect and patterns of spread of the AIDS epidemic among different regions of the world. So far, Sub Sahara Africa remains the most affected and infected region. According to the 2007 UNAIDS report, out of the total persons living with the virus , 22.5 million (more than two third) are found in Sub Saharan Africa and about 1.6 million (more than three quarter) of all AIDS related deaths occurred in the region.

Despite such alarming statistics, AIDS related mortality and the lives of HIV positive people is entering a new era because of the increasing availability of HIV treatment drugs that can prolong and improve the quality of life. Although these drugs can not cure AIDS, they can extend the lives of many productive citizens, parents and children who might have died with the onset of AIDS. As a result, AIDS in the eyes of many will not continue to be seen as a fatal and chronic disease (Van Dam & Hutchinson, 2001).

HIV treatment drugs are the outcomes of a number of clinical trials that have been conducted ceaselessly to discover the ultimate cure or vaccine for HIV. Nevertheless, from 1996 onwards, such attempts ended up by introducing the drugs currently known as Highly Active Anti Retroviral Therapy (HAART) or ART (Antiretroviral Therapy) or Antiretroviral drugs (ARVs). It was at the 11<sup>th</sup> international conference on

AIDS in Vancouver in 1996, the successes of ARVs was officially recognized and have become the standard care for PLHIV.

During late 1990's and early 2000, these drugs were available only in developed countries with high cost and the administration required a complex healthcare setting, intimate doctor patient relationship and on going counseling. For such reasons, it was generally understood that the treatment drugs only fit to the healthcare systems, life styles and behaviors of people in developed countries. Such conditions impeded the availability of ARVs in most developing countries where poor resource setting and inadequate infrastructure exists.

However, in later years, as more and more drug companies began manufacturing generic drugs, its cost reduced significantly. Furthermore, access to these drugs became a universal human right issue attracting a number of international organizations and donors to ensure accessibility to the poorest countries where the disease's burden is immense and terrible.

In 2003, WHO/UNAIDS formulated a policy with wider target of promoting the scale up of programs to deliver free antiretroviral therapy. The program was aimed at reaching 3 million people in developing countries by the end of 2005 (known as "3 by 5" initiative). "This initiative galvanized unprecedented global action to expand access to treatment and forever altered approaches to treatment and care in many developing countries" (UNAIDS, 2006:150). It has also proven the possibilities of dispensing ARVs with in the resource limited settings and where there is little knowledge about the function of treatment drugs.

Accordingly, Ethiopia was one of the 49 developing countries targeted by "3 by 5" initiative. By 2005, in Ethiopia, more than 1.3 million people were living with HIV and out of which 277, 757 were in need of ART (HAPCO, MOH 2006). With the fund available from Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria (GFATM) and the US Presidents Emergency Plan for AIDS Relief (PEFAR), dispensing free ART in Ethiopia began in January 2005 at 27 selected sites in different regions of the

country. Since then the roll out for ART has been increasing rapidly. A recent report from Ministry of Health indicated that at the end of October 2007, the number of people on ART has reached 109,552 from 13,000 at the beginning of the service delivery. Out of these total 104,535 adult users 55,888 are women and 48,650 are men and 5017 are children below 14 years old.

Currently, WHO/UNAIDS has revised its global target to “All by 2010” aiming at ensuring universal access to treatment by 2010. All those who qualify for ART should be able to get access to these drugs. Achieving this huge target is a very complex issue and posed additional challenges in most developing countries where free access to these life time drugs is ensured. The significant challenges may directly relate to the intertwined nature of the treatment drugs themselves and the existing social, cultural and economic problems in these countries (Panos, 2006).

The nature of the treatment consists of different drugs that have to be taken everyday for the rest of someone’s life with 95- 100% adherence. Each of the drugs has different rules about food and fluid that has to be taken with. Moreover, there are short and long term side effects requiring regular health checkups and also persons taking ART must abstain from unsafe sexual practices. There is a large public health concern if people on ART fail to meet the conditions mentioned above, drug resistance HIV strains will develop and spread in the society there by causing treatment failure at national and global levels. Thus, complying with all the above mentioned requirements is critical to achieve the optimal benefits from the treatment drugs.

It is also true that one’s socio cultural and economic status in the society has direct implication on the ability to live with ART. For example, if one has better education it is more likely for the person to know more about the characteristics of the medicine and if one has better income means better access to food and quality health care services which are the vital elements of living with ART. Therefore, access to ART does not only mean having many pills at hand but also about properly meeting the requirements associated with it.

Indeed this has also a gender dimension as men and women living with the virus in relative terms are not found in equal socio cultural and economic positions. These inequalities clearly underlie HIV and AIDS and also can determine details of ART. In a society where women hold lower socio cultural and economic status, it could be more difficult to live with the virus and its impacts (Nebyu, 2007). All things considered, fulfilling the requirements associated with the treatment drugs might be difficult in the face of poverty, illiteracy and gender inequality.

Therefore, a thorough study is important to reveal the gender based challenges and opportunities, beyond the increased availability and free access to ARVs. The day to day struggle men and women are confronting with in order to meet the requirements of this life time medications needs urgent attention in the context where the country is taking a major stride to scale up the service as part of the “All by 2010” global initiative.

## **1.2 Statement of the Problem**

Undeniably, HIV treatment drugs are improving and prolonging the lives of many individuals living with HIV. It is also widely hoped that delivery of free ART will further decline AIDS related mortality and will reduce the fatalistic attitude people associate to the virus. As a result, there will be increased demand for voluntary counseling and testing as well as reduced HIV related stigma (ARC, 2005).

However, such successful results from ART can only be achieved when men and women who started taking ART comply with all the requirements appropriately. Studies in developed world have shown that ARVs work best when they are taken on time, and at the right dose with nutritious foods along with regular visits to health care centers (Irwin, Millen & Fallowes, 2003). Above and beyond persons on ART should be able to protect themselves from unsafe sexual intercourses. Therefore, it is a critical matter for persons living with HIV treatment drugs to know time frequencies properly, remember doses, adjust their life style, take nutritious food and monitor drug related side effects and interactions on time.

Bearing in mind that many Ethiopians who live with HIV and got access to ART are living in poor conditions, they are more likely to face serious challenges to comply with such details of ART. The causes of these challenges partly stem out from one's gender. Compared to men, women have lower socio-cultural and economic status in our society that has direct implications to comply with the requirements of ART. Even if the treatment drugs are free to all and equal access regardless of sex is ensured, there exist gender based differences and obstacles that create problems to one's compliance to the requirements of ART. This hinders women and men from gaining the optimal benefits out of the treatment drugs.

Little has been explored about the gender dimension of living with ART. Hence it is very important to identify and create an in-depth understanding of the gender based differences, challenges and opportunities of men and women living with the HIV treatment drugs. To this purpose, the following are the research questions:

1. What are the general living conditions of men and women living with HIV treatment drugs in the sample?
2. What are the gender based socio-cultural and economic challenges men and women face in their effort to meet the requirements of HIV treatment drugs?
3. What are the existing opportunities that enable men and women to meet the requirements of the treatment drugs?

### **1.3 Objectives of the Study**

#### ***General Objective***

The overall objective of this research is to explore and describe the gender based socio- cultural and economic challenges and opportunities of Antiretroviral users at Zewditu Memorial hospital.

#### ***Specific Objectives***

The research has the following specific objectives

- a) To identify the gender based socio cultural and economic challenges ART users face in meeting the following requirements of ART (Adherence, monitoring health status, nutrition, avoidance of Khat and alcohol and practicing safe sex).
- b) To assess opportunities that enable men and women ART users to meet the day to day requirements of the treatment drugs.
- c) To describe how the underlying socio-cultural and economic differences between men and women has implication over their life with ART.

#### **1.4 Significance of the Study**

Since the beginning of dispensing free ART service in Ethiopia, enormous efforts have been exerted to scale up the services to all eligible persons living with HIV. However, increasing the availability of ART must not be the only issue to deal with; sufficient attention should also be given on how men and women are living in real terms while meeting the requirements associated with the treatment drugs. This research in fact has given due importance to this aspect of the issue.

Particularly, in the face of persistent poverty and gender inequality, living with HIV and its treatment drugs is understood to be a very intricate matter. As compared to men, women have already struck hard by the intertwined nature of poverty and HIV. ART being a recent experience to our country has also brought a new challenge for them. Thus, this research will produce insights over the challenges and opportunities of women on ART in relation to men.

Beyond its academic purpose, this research will also inform policy makers, donors, government and non government organizations and the public in general about the gender dimension of living with ART. It can also indicate critical areas of intervention to maximize the optimal benefits the country can achieve from the provision of free treatment drugs.

#### **1.5 Limitation of the study**

The study is undertaken among specific target group with limited scope. It primarily focuses on identifying gender based socio-cultural and economic challenges and opportunities, whereas, living with HIV treatment drugs in broader sense involves psychological, physiological and other complex issues. Therefore, this study did not exhaustively go through all such complexities that bear up on one's ability to comply with the requirements of the treatment drugs. Moreover, it deals with the experiences of both men and women who are above 14 years old and live in urban area. Thus, it might not represent cases of many people in rural setting where aspects identified here might have a very different picture there.

## **2. REVIEW OF RELATED LITRATURE**

This section is organized in such a way that it gives basic information related to HIV treatment drugs and gender related concepts and proceeds to highlighting the overall condition of Antiretroviral treatment in Ethiopia. It describes the link among gender, HIV and ART. Then after, the user side requirements of ART which include adherence, monitoring health status, nutrition, being free from Khat and alcohol use and safer sexual practices are reviewed from gender perspective. Finally, feminist concerns on living with HIV treatment drugs are presented.

### **2.1 Operational Definitions**

#### **2.1.1 HIV and AIDS, Antiretroviral Basics**

##### ***HIV, CD4 and AIDS***

The human Immuno deficiency virus (HIV) directly attacks the CD4 cells that play a major role in maintaining the body's immune system. CD4 cells are the very important types of white blood cells that protect the human body from any types of infections (Panos, 2006). After several years of HIV infection the number of CD4 cells

falls below normal count (800-1000) to (below 200) per cubic millimeters leading the body to become susceptible to any type of infections. This condition is identified by health professionals as the stage of AIDS. AIDS is a group of diseases manifested in the person who has HIV.

### ***Anti- Retroviral-Therapy (ART)***

It is the administration of at least three different medications known as Anti-RetroViral drugs (ARV) in order to suppress the replication of HIV so that CD4 levels are maintained to keep the body from infection. Treatment with these combinations of drugs is also known as Highly Active Antiretroviral Therapy (HAART)( ART information tool kit 2005). Treatment with HAART usually reduces the amount of virus in patient's blood stream, allows CD4 cells to be replenished and restore immune function, helping the body to overcome opportunistic infections. However, HAART is not a cure and must be taken for life time. Currently, there are over 20 types of ARVs in 4 different classes' defined according to the method by which they attack HIV, and many more types of ARVs are evolving every year.

### ***Viral Load and CD4 Count***

Viral load refers to the amount of HIV virus in the patient's blood stream. In the presence of ART viral load is expected to decrease to undetectable levels and when there is poor adherence and treatment failure viral load increase which is an indication of diseases progression. Viral load and CD4 counts are the major indicators of treatment success. As Viral load decreases CD4 cell count increase and vice versa.

### ***Opportunistic Infections (OI)***

When the body's immune system weaken as a result of HIV attacking CD4 cells, the body become more susceptible to different diseases and infections caused by bacteria and virus that were awaiting opportunities of weakened immune system . Common OI are Tuberculosis, herpes, any bacterial or fungal infections.

### ***Drug Regimens***

It refers to formulated schedule of medication, there are first, second, third line regimens each with combination of different pills from the same class. Patients first begin with first line regimens and when drugs from these regimens can no longer work for different reasons, they move to second line regimen and when this line of treatment fails to third and the fourth line is the last resort. Each drug regimens have specific rules about food and time of taking (ART information tool kit, 2005).

### ***Viral Drug Resistance***

If persons on ART did not take their medications properly because of various reasons, there is a high tendency of developing drug resistance meaning that drugs can no longer suppress the virus and the immune system will be weakened greatly resulting disease progression and decreased survival. A person might also contract drug resistance HIV through unsafe sex with the person who has already developed drug resistance (WHO, 2006).

### ***Post Exposure Prophylaxis treatment (PEP)***

It refers to administering ARVs for the purpose of preventing HIV infection after occupational exposure to infected blood and if women and girls encounter coerced sex or rape. Post exposure prophylaxis (PEP) is a month-long course of medication for people who have been exposed to the HIV virus. To be most effective, it should be started within 72 hours of exposure to HIV infected blood (ART guideline, 2005). Therefore, it has brought great relief to health care providers and for raped women.

### ***Drug Interaction***

Some types of ARVs may interact with other types of drugs including traditional medicines which might produce toxicities. Hence persons on ART are strongly

prohibited not to take additional types of medications without consulting their doctors.

### **2.2.2 Basic Gender Concepts**

#### ***Sex and Gender***

Sex refers to the physical and biological differences between men and women. Gender refers to the socially driven differences between men and women, and identifies the social relations between them in the society. It also refers the relationship between sexes that is constructed on the values, beliefs and customs of a society and that influences women's and men's differential roles and responsibilities and their access to knowledge, resources and/or services. Since gender is a social construct, it can be changed. ( Moser, 1993)

#### ***Gender roles***

The relationship and responsibilities of men and women based on expectation regarding their rights and duties in the society. Gender roles are learned through socialization processes that specifically train male and female in different behavioral categories and division of tasks that are considered appropriate for them according to the values and norms of the society. (Moser, 1993)

#### ***Gender relations***

Refers to a complex system of personal and social relations of dominations of power through which women and men are socially created and maintained interdependently (VSO, 2007).

#### ***Gender based differences***

Any type of differences anchored in the social and cultural construction of what is to be a "woman" and what it means to be a "man", differences manifest in all spheres of life in terms of roles, access to productive resources and opportunities, needs and priorities, participation etc. (Khatleen, 2005).

## **2.3 HIV/AIDS and Anti Retroviral drugs in Ethiopia**

Ethiopia is among the Sub Saharan African countries where a large number of people live with HIV. According to Federal HIV/AIDS Prevention and Control Office (HAPCO) single point HIV prevalence estimate, in 2007, the national adult prevalence was estimated to be 2.1% with the urban rural prevalence 7.7% and 0.9% respectively. The total number of people living with the virus in the same year was estimated to be 977,394. AIDS also killed an estimated 71,902 individuals in the same year.

Until recently, the major concern on HIV/AIDS was on prevention of new infections through various approaches with little attention given to those who have been already living with the virus. Nevertheless, prevention efforts must be accompanied by treatment of those who live with HIV (HRSA CARE ACTION, 2003).

It is recognized that treatment for HIV positive individuals after diagnosis has different stages which include an emphasis on positive life, treatment of opportunistic infections, provision of antiretroviral drugs and palliative and end of life care services (Whiteside & Sunter, 2000). However, in Ethiopia as in many other developing countries the availability of these chains of comprehensive care and treatment services are either non existent or only one or two of them are available.

The introduction of ART is indeed a breakthrough and step forward in the whole set of HIV/AIDS response in the country, it has brought a new hope for those who are living with the virus. Without access to ARVs, people with HIV often die within one or two years of the onset of AIDS (Panos, 2006). The Ethiopian Ministry of health has also anticipated that in the long run ART will have profound impact on AIDS related deaths and would increase life expectancy of the country that partly has dropped as a result of HIV and AIDS.

Before 2003, some people in Ethiopia got access to ART through black market but the official ART service began in Ethiopia in July 2003 on fee bases costing (\$289-\$346 per month). According to MOH (2005) report at that time only 2% (3000) PLHIV got access to the service from 12 hospitals. Clients were mainly educated and well to

do men who live in urban areas. But with the “3 by 5” and concerted effort of Ethiopian Ministry of Health as well as other international donor organizations, free ART service launched in January 2005 in 49 additional sites in different regions. Currently, there are 272 ART sites all over the country.

According to the Ethiopian AIDS resource center web site, as of the end of October 2007, out of the total 258,264 people who need ART in Ethiopia 109,552 are able to access it. Out of the total ART service recipients 55,888 are adult women, 48,650 are adult men and 5017 are children below 14 years old. The ministry of health has a plan to put 320,000 persons on ART by the end of 2008.

Since the beginning of ART service in Ethiopia, the Ministry of Health in collaboration with other international NGOs has formulated important national documents to guide and coordinate various efforts targeting HIV and AIDS treatment. The first important document published in 2003 was the “Policy on the supply and use of Antiretroviral drugs in Ethiopia”. This policy provided the bases for the expansion of treatment in the whole country. Later in the same year “Guidelines for use of Antiretroviral drugs in Ethiopia” was published. This guideline forwarded the primary and secondary goals of provision of ART in Ethiopia. Accordingly, the following are the primary goals of ART service in Ethiopia (MOH, 2003: 3)

- Maximal and sustained suppression of viral replication
- Restoration of the immune system
- Reduction of HIV related morbidity and mortality
- Improvement of quality of life
- Prolong survival

The secondary goal is to decrease the incidence of HIV by

- Increasing uptake of VCT with its benefits to the individual, family and community
- Reducing the risks of HIV transmission from mother to child
- Changing the perception of the community about AIDS from...uniformly fatal disease to...manageable chronic disease

- Raising the hope of community, there by reducing stigma and discrimination and ensuring enhanced participation of the community and PLWHA in HIV/AIDS control and prevention
- Reduce transmission of HIV at the community level

The guideline was also a land mark in indicating who qualifies for ART, the selection criteria, the type of approved ARVs in Ethiopia and conditions of switching to other drugs in the case of treatment failures.

Based on WHO public health recommendation, currently there are three class of HIV treatment drugs approved to be distributed in Ethiopia. Most patients begin from the first class regimens which are composed of three different types of pills. There are two basic conditions to switch patients to second line regimens these are: in the case of drug resistance and treatment failure. Patients will be forced to switch to second class regimens which are more complicated with serious side effects. Third class drugs are more expensive, much more complicated and the last resort in ART treatment in Ethiopian contexts. If patients reached to the third class drugs no other alternative treatment options are available (ART guideline, 2003).

Another important document published in 2005 was, the National Strategic Communication Framework which was aimed at guiding and supporting ART communication activities in Ethiopia. The communication activities were designed at three levels environment, community and individual levels. A road map to year 2008 in ART expansion was also designed to increase the roll out for ART.

Despite the existence of such appropriate and sound national ART documents provision of ART service in Ethiopia is constrained by various factors that can be seen from both the provider and client perspectives. From the provider side, as a study conducted by Dawn of Hope (2006) (Association of persons living with HIV) revealed that there are few ART trained doctors, nurses, pharmacists, laboratory technicians and counselors who are already burdened with taking care of other patients. Moreover, the health facilities that provide ART do not have comprehensive

services, such as laboratories are not equipped with enough number of CD4 count and viral load measuring machines. Added to this, lack of ongoing adherence counseling and “treatment literacy” has limited clients’ ability to properly adhere to treatments (Panos, 2006). Except the efforts of few NGOs, there is also lack of adequate nutritional and psychosocial support to persons on ART.

In addition, all PLHIV cannot access ART, because ART is initiated exclusively by the doctor after a thorough assessment of both clinical and psychosocial conditions of the patient through subsequent visits. The clinical assessment is based on World Health Organization definition of AIDS stages composed of different kinds laboratory tests that include patients CD4 count, existence of opportunistic infections, pregnancy and psychiatric illness. The non clinical assessment is about patient’s psychological readiness, willingness to properly adhere with ART (MOH, 2003). Therefore; those who pass through such examinations are only become eligible to start ART.

From the client standpoint, ART service is unlikely to be available to all those in need, PLHIV must reach to the stages of AIDS, fulfill certain social and economic criteria. However, MOH gave priority for the following three groups irrespective of the above mentioned criteria:

- Those who are the sickest, but whose treatment with ARVs can lead to improved health
- Those who are most vulnerable such as children and
- Those who fall under national strategic priorities such as Prevention of mother to child transmission of HIV and post exposure prophylaxis ( in case of occupational exposure to HIV and rape)

Indeed access to ART in Ethiopia depend on a lot of factors, the action research by Dawn of (2006) mentioned earlier indicated that patients ability to go for voluntary counseling and testing, disclosure of HIV positive status to at least one family

member, incurring some amount of expenses for traveling to health facilities and laboratory tests are identified to be the major client related problems in ART service in Ethiopia.

It is also mentioned that stigma and discrimination still persist affecting ART service from two opposite directions. Since persons on ART regain their health and return to their usual life stigma associated with AIDS sickness is assumed to decrease. On the other hand, fear of stigma may prevent persons on ART from taking their medications properly. As studies showed that, many PLHIV are uncomfortable to take their pills in the presence of other individuals because of stigma (ICRW, 2006; Dawn of Hope, 2006; Panos, 2006).

Moreover, there are growing myths and misconceptions about ART in Ethiopia that are being reported to be obstacles of accessing treatment as well as reasons for interruption of taking ART. For example, some people still think that ART is a cure; some others say that ART is bad for pregnant women because it can cause deformation on the fetus. Some others believe drugs are toxic and it is better to die than taking them. Others believe ART should not be taken with religious medications and a choice must be made to one of the two (Dawn of Hope, 2006; Panos, 2006; Arega, 2007; Ermias, 2007). Such kinds of misconceptions prevent individuals from seeking ART services and maintaining proper adherence to their treatment.

The poor socio- cultural and economic statuses of PLHIV have also imposed multifaceted challenges to the provision of ART (MOH/ HAPCO, 2005). It is true that with out education, better income, nutrition and supportive environment it is difficult to comply with all the requirements of ART. Thus, ART service in Ethiopia is operating with in such complex and interrelated circumstances.

### **2.3 Gender, HIV and Antiretroviral Therapy**

Literatures consistently indicate that HIV/AIDS and gender are entwined; the increased biological and social vulnerability of women to HIV has resulted in the greater number of women living with the virus than men. According to UNAIDS 2007

AIDS epidemic report, in Sub Saharan Africa 57% of adults living with HIV were women. Worldwide, 76 % 15-24 years old with the virus were females. Every year, approximately 2.2 million pregnant women living with HIV give birth and an estimated 700,000 babies acquire the virus from their mothers during pregnancy, birth or through breast feeding (UNAIDS, 2007). In addition, numerous researchers have noted that because of their low socio cultural and economic status women have carried the consequences of the AIDS crisis disproportionately.

In this era, the availability of ART has opened widows of hope in mitigating the impact of AIDS. Particularly, the delivery of free ART supposed to bring reduced disease burden, improved life and extended survival of men and women living with the virus. ART has brought exceptional advantages to women as it can effectively prevent mother to child transmission of HIV as well as their contracting the virus as a result of coerced sexual encounters (WHO, 2005).

Moreover, Ross et al., (2001) indicated that the large scale provision of ART has indirect benefit for women. As caring for the sick is one of their social responsibilities, with the availability of ART, AIDS patients will no more bedridden and might not be dependant on women for care. Furthermore, in many societies husbands are the usually bread winners to the household, their improved health status and getting back to work means the burden on women would be lessened.

However, every step in getting access and living with this life long treatment drugs is accompanied by different standards that in return depend on the individual socio-cultural and economic status in the society (Silvester et al., 2005). It is clear that the existing gender based differences, economic disparities, patriarchy, violence against women and sexual power differentiations have direct repercussion over the ability of women to meet the conditions of ART (Donald & Hurely, 2002; ICRW, 2006; Esplen 2007). Thus, it is found important to review the user side requirements of ART from a gender perspective.

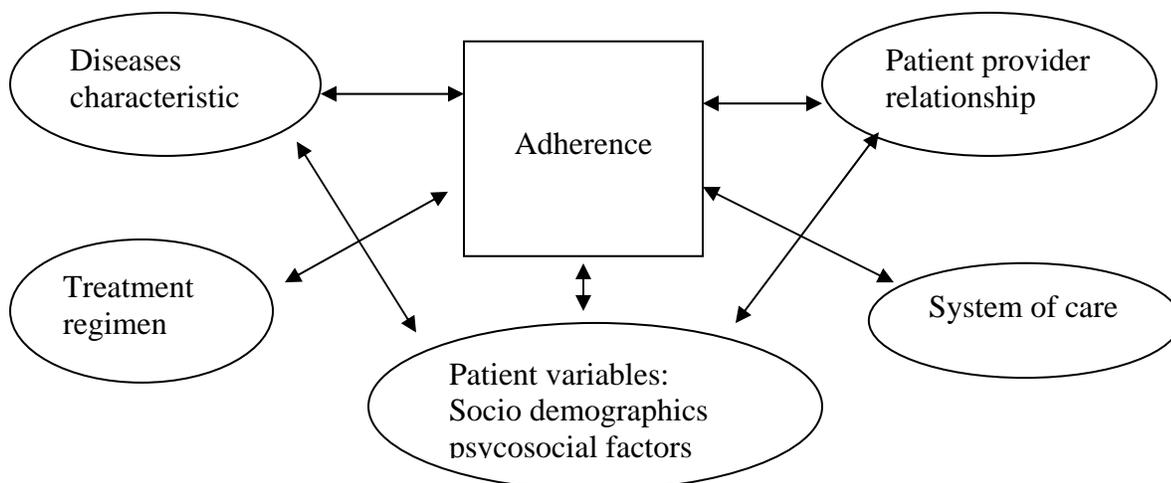
## 2.5 User Side Requirements Associated with ART: From gender perspective

Once ART is initiated it can not be discontinued. Because of this, living with HIV treatment drugs entails a range of obligations and commitments from both the side of the provider and user. For the context of this research, the user sides of the requirements from a gender perspective are reviewed. Therefore, persons who became eligible to start the treatment under clinical and non clinical assessment are required to meet the following matters properly.

### 2.5.1 Adherence

Adherence is defined as “patient’s ability to follow a treatment plan, take medications at prescribed times, frequencies and specified doses as well as follow restrictions regarding food and other medications” (Population Council, 2004: 13). ART exclusively requires strict adherence about 95 to 100% (missing no more than one dose per month). Persons on ART should follow the instructions on drug regimens as exactly as prescribed by the health provider. They should keep drug taking time properly, identify mixes and take appropriate dosages with certain amount of food and fluid in order to effectively suppress viral replication and maximize health benefits out of the drugs.

Adherence is very complex behavior that can be affected by a range of factors that are internal and external to the patient. The following diagram illustrates determinants of adherence.



Source: J R Ickovcs & C S Meade, in Population council, 2004

As the above diagram demonstrates that no factor stands alone determining adherence, each has various directions to influence patient's condition to take medications properly. Moreover, studies showed that difficulties to predict adherence based on a single factor shown in the diagram.

Non adherence to ART has serious consequences both to the individual as well as the society at large. Non adherence according to Population council (2004) refers to the following elements:

- Missing one dose of a given drug
- Missing multiple doses of one or more prescribed medication
- Missing whole day treatment
- Not keeping appropriate time intervals
- Not keeping dietary and fluid restrictions

On the individual side, non adherence would likely to result in inadequate suppression of viral replication, continued destruction of CD4 cells, progressive decline in the immune system and the development of drug resistant HIV strains that have the ability to multiply despite the presence of ART. This resistance could be for one or more treatment drugs in the same class which is called "cross resistance" there by causing an increase in viral load and at last resulting in the over all treatment failure (From: [http://www.avertrisk.com/HIV\\_info/art/resistance.htm](http://www.avertrisk.com/HIV_info/art/resistance.htm)). WHO in general ruled out the complications as follows;

This condition necessitates changing regimens. However changing to new regimens after treatment failure complicates the treatment requiring more pills, complex side effects, dietary restrictions, toxicity and dosing complexity. In this case, the future treatment options of the patient are

seriously limited. Therefore, patients are in danger of significant viral resistance, disease progression and the over all treatment failure that would clearly result in death (WHO,2006: 27).

These individual consequences of non adherence has also serious implication to the larger society, where the drug resistant HIV can be transmitted to both seropositive and negative individuals through unprotected sex causing unexpected out break of drug resistant HIV strains.

Moreover, the presence of drug resistant strains will result in increased use of Second line and third line regimens which are in general more expensive economically. Thus to minimize such complex and severe risks patients must adhere to their treatment drugs exactly as prescribed by their doctors (WHO, 2003).

However, adherence to lifelong drug regimens is difficult under the best of circumstances, leading many to argue that adherence will be even more problematic in settings where poverty, lack of education and stigma pose additional challenges (Irwin, Millen & Fallows ,2001; Fleischman,2004; Esplen 2007; Goudge etal., 2004).

Poverty influence adherence in a way that if persons on ART are not able to fulfill the necessary food and fluid requirements associated with their type of ARVs as it was mentioned above, it is classified as non adherence. Moreover, lack of education and information about side effects, interaction and benefits of ART may result in reluctance of patients' proper adherence to their medications (UNAIDS, 2006).

Studies show that fear of stigma has direct influence on ART adherence. Many PLHIV fear to take their medicine in the presence of other individuals, for this reason they might skip doses or do not keep the proper time to take their drugs (Panos, 2006). In general, adherence is one of the basic requirements of living with ART and it is influenced by various factors that are complex and interrelated.

### **Gender and Adherence to ART**

Previous researches on adherence indicated that it is impossible to predict level of adherence based on patient demographics such as age, gender, ethnicity, and socioeconomic status, as to which patient men or women can achieve high adherence to ART. There is just no correlation between demographic characteristics and patient adherence levels (HRSA CARE ACTION, 2005). Thus, it is difficult to state that either men or women from different socio cultural and economic background more or less adherent to ART.

However, according to Emily Esplen (2007) women's entrenched social, cultural and economic inequality with in their relationship with men can be a barrier to effectively adhere to their medications. Socially constructed gender roles have their own impact in limiting adherence to ART. Women's roles and responsibility in the household, their tied up day to day schedules may hinder them from taking their medication at prescribed frequencies. In addition, as the physical and psychological burden of HIV/AIDS care including those orphaned children and grandparents falls heavily on women as carers may experience high level of stress and exhaustion which significantly impact upon their adherence to their treatment (Kathleen, 2005; Esplen,2007).

Furthermore, the experience of social stigma has affected HIV positive poor women more than men in similar circumstances, women are blamed for being vectors of the disease to their partners as well as to their children (Silvester et al.,2005; Nebyu, 2007; Esplen,2007). As a result, they may face serious difficulties in adhering to their medications, particularly those women who gave birth and employ other infant feeding options than breast feeding may encounter problems of hiding their positive status and adhering to ART.

As mentioned earlier, patients' adequate knowledge and information about the functions and limitations of ART is vital for better adherence. Despite such facts women have limited access to education and information as compared to men this might have restricted their rigorous adherence to ART (Silvester et al., 2005).

Moreover, lack of adequate information about side effects also results in their discontinuation of medications without consulting health care providers.

### **2.5.2 Nutritional Requirements**

Food is one of the basic requirements for the survival of all human beings. But it is widely known that regular access to adequate and varieties of food depend on complex socio cultural, economic and political factors. In Ethiopia, poverty is often sighted as the major factor that limits the availability of nutritious food at household and national levels. Though the level varies malnutrition is a very common phenomenon among children, men and women in Sub Saharan Africa (UNAIDS, 2007).

This condition further exacerbated by the emergence of HIV epidemic. According to Piwoz and Preble (2000) who made an in-depth study on the relationship between malnourishment and HIV in Sub Saharan Africa, asserted that HIV infection compromises the nutritional status of infected individuals and ,in turn, poor nutritional status affect the progression diseases increases fatigue, and it decreases physical activity and work productivity of PLHIV.

The relationship between nutrition and HIV become stronger when the patient starts ART that has a direct interaction and specific rules on food. ARVs can interact with food and nutrition in a variety of ways, resulting in both negative and positive outcomes. Malnutrition can compromise the efficacy of ART, in such a way that it can limit medication absorption, metabolism or excretion (Castelman, Seumo & Coggill, 2004).

Besides, each types of treatment drug has different rules about food some work better on a full stomach, while others need an empty stomach to be properly absorbed and some others require high intake of protein and milk while others avoiding garlic and other specific nutrients. Furthermore, some of the medications must be taken after certain hours of meal (Van Dam & Hutchinson, 2001; ART info.

tool kit, 2005). To this need, ART users should be well aware as to which type of food their regimen fits best and must be able to take adequate and nutritious foods.

In addition, if persons on ART lack access to adequate food, they are less likely to be able to adhere to a daily treatment regimen (UNAIDS, 2006). They may face serious dilemmas whether to take the drugs without food or become desperate and resort to quit the drugs. Moreover, a study on the social and religious challenges of ART users by Ermias Bezabih (2007) indicated that the food intake of persons on ART might also be affected by different spiritual practices like fasting and holy water treatment in Ethiopian contexts.

Generally, it is emphasized that “nutrition has to be the first line of treatment of HIV” and part of the comprehensive HIV care (UNAIDS, 2006). Thus, persons on ART are highly recommended to take nutritious food with the “Every bite counts” rule meaning that each meal should consists of appropriate amounts of calories, proteins, vitamins and other important nutrients and should be taken at the prescribed times (Castelman, Seumo & Coggill, 2004).

### **Nutrition and Gender**

As stated earlier, nutrition is the crucial component of living with ART. But access to nutritious food may vary among men and women because of the socio-cultural and economic reasons. The socially constructed gender roles of men and women interact with their biological roles to affect the nutrition status of the entire family and of each gender (Oniang's & Mukudi, 2002).

Following dietary rules and restrictions associated with certain types of ART may become difficult for both men and women in the context of poverty and with the rising cost of living. However, studies have proved that women in many contexts are struck hard by poverty and HIV that can further limits their access to better food while living with ART.

In addition, although studies are not available in Ethiopian situation, in many contexts cultural norms train women to eat last after feeding all their family members and what is more astounding about such norms is that women choose to give the best foods to their husbands, brothers and children than eating for themselves. This culturally constructed mind set can harm women even if it seems adequate food is available in the household.

Women's conditions get worse if she becomes pregnant as (Pioz & Perble 2000) affirmed that HIV/AIDS and malnutrition are inextricably interrelated; malnutrition increases the risk of HIV transmission from mothers to babies and the progression of HIV infection. In turn, HIV infection exacerbates malnutrition through its attack on the immune system and its impact on nutrient intake, absorption and utilization. Furthermore, malnutrition may result in increased susceptibility of individuals to opportunistic infections.

Finally, maintaining good nutritional status in the context of poverty and HIV could be a difficult matter for many individuals, added to this the cultural norms and values may also influence men's and women's access to food differently.

### **2.5.3 Monitoring health status**

Monitoring health status is a very important component of living with ART. In fact monitoring the health status of PLHIV starts before initiating treatment while the health provider assesses whether the person fit to eligibility criteria or not. Once treatment is started there are four essential aspects of monitoring these are therapeutic response (drug side-effects), drug toxicity, adherence to medication regimens and monitoring for viral resistance (Degu, 2006).

ART has different side-effects which need regular attention. Side-effects happen when the drugs affect the body in ways other than those intended. Most of the anti-HIV drugs have known side-effects, but this does not mean that everyone who takes them

will experience side-effects (WHO, 2004). Moreover, Ross et al., (2001) asserted that it is impossible to predict if one is likely to experience side-effects or not.

Commonly identified short term side effects are headache, nausea, vomiting, fatigue, diarrhea, loss of sleep and appetite. Such side-effects are mild and disappear within 2- 6 weeks as the patient continues taking the drugs or switched to a different regimen. While the long term side effects are much more serious and complicated some types of drugs can cause severe anemia (low levels of red blood cells), neutropenia (low level of one type of white blood cells), fat redistribution syndrome and liver enlargement (Van Dam & Hutchinson, 2001). Therefore, it is imperative for persons on ART to carefully monitor their health status in relation to such drug side effects.

Not only side effects require monitoring, but also drug interaction with other medications also needs to be checked at the right time (Panos, 2006). Some people may take additional drugs without consulting their doctors and in other cases people may take traditional medicines which might interact with ART producing toxicity in different body organs. Unless patients are adequately informed and are able to monitor such conditions such toxicities might result in death.

The other important factors that must be monitored are viral load and CD4 count which are inversely related and indicators of the effectiveness of ART on the individual (HRSA CARE ACTION, 2003). The World Health Organization in this regard recommends persons taking ART in resource constrained settings should check their CD4 and viral load status at least every 6 months.

In addition, going to health care centers is also important for adherence counseling, solving problems of adherence, with the consultation of health care provider (Silvester et al., 2005).

Given such variety of necessities associated with monitoring health status many individuals on ART may not go to health centers due to economic, social and cultural

reasons. Moreover, the health seeking behavior which is defined as the sequence of remedial actions that individuals undertake to rectify perceived ill health can influence an individual's decision to seek treatment timely (Van Dam & Hutchinson, 2001). In fact, among those complex factors that affect health seeking behaviour, social norms and behaviours are included. According to Arega Gera (2007) this implies that even if treatment and information are available, individual held values and norms may deter one from accessing health services timely.

### **Gender and monitoring health status**

As stated above, monitoring health status regularly is one essential requirement for persons on ART. Drug related side effects and reactions should be reported as early as possible in order to either change regimens or quit drugs. However, monitoring health status is associated with different costs in terms of money, time and physical health. In most cases, women do not have independent financial resources or their incomes tend to be low as a result they may fall in difficulties to cover transportation and laboratory costs in the health centers (ICRW, 2005; Donald & Hurely, 2002).

Moreover, because of their ascribed gender roles women are highly attached to the household chores, child care and care for the sick that might not give them extra time to go to health centers. Above and beyond, studies showed that women are culturally trained to put first their children and family health rather than their own (Silvester et al., 2005; Esplen, 2007; El-Sadr, 2001).

Women on ART have a special case that needs monitoring also, the presence of pregnancy that has potential to complicate their health status. HIV positive pregnant women need particular follow ups because certain types of ARVs are not suitable in the presence of pregnancy and they must be switched to different drug regimens that can be helpful to both the mother and fetus health (Ross et al., 2001).

Furthermore, there have been studies that demonstrate due to biological reasons the adverse side effects of the HIV medications are more commonly reported by women than men. Women also have an increased risk of adverse drug reactions from ART

(From: [http://www.avertrisk.com/HIV\\_info/art/resistance.htm](http://www.avertrisk.com/HIV_info/art/resistance.htm)). Therefore, monitoring health status has an additional aspect for women than men.

#### **2.5.4 Substance abuse**

ART users are strictly required to abstain from the use of Khat and alcohol (most commonly used substances in Ethiopia). Particularly they are expected not to smoke, chew Khat or take any other types of narcotics. This is because the drugs might interact with the medications and produce toxicities that exacerbate health complications resulting in decreased survival (ARC, 2005).

On the other hand, researches showed that patients with heavy alcohol intake or active drug use have problems in adhering to treatment – forgetting to take medications on time and correctly (Population council, 2007). In addition, high alcohol and drug use is associated with loss of appetite and sleep which can cause non adherence to medications (Goudge et al., 2004).

Khat and alcohol use have been often sighted as one of the possible driving force for the spread of HIV including drug resistant virus. It is clear that persons who take drugs and alcohols are unlikely to practice safe sex. In this regard, a study by Kebede et al.,(2005) and Dawit et al., (2005) revealed the strong association between alcohol and Khat use with risky sexual behavior in Ethiopian contexts. Thus with such behaviors persons taking ART might expose themselves to drug interaction as well as could be the vectors of transmitting drug resistance strains through unsafe sex.

#### **Gender, Khat and Alcohol use in the context of ART**

As stated before, patients on ART are required to avoid Khat and alcohol because of drug interaction that could weaken their health status. However, some persons on ART are unable to refrain from their addiction after starting ART (Dawn of Hope, 2006). Although there is no national statistics available on the level of Khat and

alcohol use, critical observations to Ethiopian context reveal that more young men are found to be addicted to alcohol drinks and Khat than women. This condition obviously leaves men who are taking ART in a more serious health complication than women.

Moreover, men's risky sexual and violent behaviors induced as a result of drug and alcohol use might expose women to HIV and its drug resistant strain as well as to unwanted pregnancy (Maundeni, 2005). Therefore, both men and women can be victims of consequences of alcohol and drug use but the situation of women is determined by factors that are out side their control.

### **2.5.5 Safer Sexual Practices**

Obligation of safer sexual practices is not only for persons on ART, but also for all sexually active age group who are in the threat of contracting HIV and other sexually transmitted diseases. However, one would expect an HIV positive diagnosis to have a profound impact on sexual behavior of the individual. Hence according to Green (1994: 46)

HIV positive individuals have to reassert their sexual identities and re-establish sexual relationships with in a hostile and frightening environment related to their potential either to infect others or contract other strains of HIV that might facilitate their disease progression. This implies that PLHIV must be extremely careful to practice safe sex so that to protect themselves as well as others.

“Safe sex” is usually a contested term as to what it constitutes and to whom it applies. In fact, many HIV prevention messages emphasize the value of safe sex either in terms of faithfulness to only one partner or condom use. In any way safe sex implies that “taking precautions during sex that can keep one from getting a sexually transmitted disease (STD), or from giving an STD to the partner” (HARSA CARE ACTION,2003: 31).

But in the context of living with ART, safe sex is exclusively about abstinence, consistent and correct use of condoms. But using condoms widely vary depending on

age, education, personal choice, marital status, availability and other related social issues.

It is widely witnessed that in the case of married couples there is high reluctance to use condoms as marriage is based on trust and which generate safety (Panos, 2006). With in such conditions, there exists high risk of exchanging different strains of HIV between couples including the drug resistant strain.

ART is proven to be effective in making PLHIV healthy and functional, returning them to their previous day to day life after serious illness. Despite such great advantage, individuals on ART remain infectious even in the case of complete adherence. Thus, this condition has a larger implication to the sexual behaviors of persons taking ART.

Growing studies in poor African countries indicate that many people who recovered because of ART have continued their risky sexual behaviors. This condition perpetuate the spread not only the HIV virus but also drug resistant HIV strains and in anyway those who are exposed to resistant virus will never benefit from ART. In this regard (WHO 2006: 25) ruled out the danger like the following:

...when exposed to medications, HIV changes or mutates over time. If a person is re infected with a strain of HIV that is different from the strains already present or if a mutated HIV type is introduced into the body through unsafe sex, treatment will be much more complex and potentially ineffective. This in fact would spread to the community – to society at large resulting the over all treatment failure at the global level creating the major global health crisis.

Hence to prevent the spread of HIV and its drug resistant strain and derive good benefits from ART, persons on ART must be able to practice safer sexual intercourse.

### **Gender and safer sexual practices in the context of ART**

As stated above sexual behavior is one important matter that should be considered carefully while living with ART. But in many cases men and women do not have equal power to practice safe sex. In Ethiopia, as else where in the world, because of cultural norms sexual relationships are dominated by men. Because of poverty, economic

dependence and gender based power differences women are denied the power to negotiate safe sex even when they know risks are involved (Nebyu, 2007).

According to Burnett et al., (2007) women are socially made unable to refuse sex while men are able. The socialization processes that grant men to be expressive and initiators of sexual relations have made women submissive and less expressive of their sexual desire. Furthermore, a woman's refusal to sex might be followed by violence this violence even goes to the extent of rape. In fear of such violence, women expose themselves to unprotected sex. Even if they insist on condom use the decision is exclusively at hands of the man. Women in general lack the power to use male condoms ( WHO,2006).

Therefore, because of the gender dynamics and partly biology, women are not always in the position to practice safe sex. Instead their decision about when, how and where to have sex is determined by their male partners. This indeed makes women more vulnerable to HIV infection and re-infection more dangerously contracting drug resistant HIV strain (Kathleen, 2005; Kyomuhendo, 2005).

The availability of Post Exposure Prophylaxis (PEP) has generated a new hope in preventing HIV infection as a result of coerced sex or rape. However, despite such advantages how many women do have the information regarding the existence of such services, how timely they come to access the services as the treatment must be initiated within 72 hours of exposure. Such concerns still remain far unanswered.

In any way, researches have shown that as compared to men, women's lack of decision making power over their own sexuality has a potential to compromise their ability of meeting the "Safe sex" requirements of ART.

## **2.6 Feminist Concerns about living with Antiretroviral Therapy**

Since the provision of HIV treatments drugs is a recent phenomenon the writer faced difficulties to find a fully articulated theory that directly connects gender issues with

the use of Antiretroviral therapy. Hence, the study will base it self in different sensitizing concepts developed and raised by feminists who criticize the existing gender parity and promote equality for men and women in all spheres of life. These concepts are adapted from a paper developed by Silvester,L et al.,( 2005) and presented in an international meeting “Ensuring Universal Access: User fee and free care Policies in the context of HIV treatment” on March 2005 in Geneva.

The concepts are condensed to fit to this paper and presented as follows;

- Many types of ART drugs require certain amount and types of food. In situations where poverty limits the amount of food available and where women are the last to eat, it can be almost impossible for them to take ART effectively without additional support.
- Even if HIV treatments are free of cost, other indirect costs can prevent women from getting the optimal benefit out of the treatment drugs. These include frequent journeys to health facilities can be both expensive and difficult for them as they are tied up with day to day domestic responsibilities and caring for the family; they find it difficult to leave their family to travel to clinics. Moreover, since poor women have less access to financial resources, even they might not have enough money for transport to monitor their health status regularly.
- The stigma of living with HIV/AIDS, although affecting both sexes, because of social and cultural reasons, it is often more extensively directed against women than against men. This stigma is more likely to result in reduced adherence to the treatment drugs among women than men.
- Compared to men, women do not have sufficient information and knowledge on how to treat symptoms of side effects and may be misinformed about the risks of ART.

- Women may also have limited control over their mobility and time. A woman may not be able to access health services because society restricts her movement or a woman's husband may prevent her from obtaining treatment and follow ups after treatment is initiated.
- The low status of women in the household and in society often means that they are not used to expressing their own needs, can not negotiate safer sexual practices, have their own income to buy food or go to health centers as they desire.
- Because of the gender dynamics and its intersection with class and race poor women living with HIV are more likely to face violence from husbands, relatives, employers etc. This violence may even go to the extent of denial of their medications.
- In the context of ART, consistent and correct use of condom is the only option available to practice safe sex. However, in the situation where the focus is largely on promotion of male condoms and ignorance on female controlled methods may result in women's increased vulnerability to drug resistant HIV strain and treatment failures.

In general, even if HIV treatments are becoming widely available without fee and women's equal access to the treatment is ensured, all the above mentioned feminists concerns translated in to women's day to day life, it becomes difficult for them to benefit from the treatment drugs as equally as men.

### **3. METHDOLOGY**

#### **3.1 Design of the Study**

The study mainly employed qualitative approach with a quantitative support. The need to utilize qualitative approach to this study basically arises from the exploratory and descriptive nature of the research. Obviously, exploration requires going deep in

to people's day to day life, interactions and expression of past experiences that can better be captured through gathering qualitative information. Moreover, qualitative research is based on methods of data generation which are both flexible and sensitive to the social contexts in which data are produced rather than rigidly standardized or structured or entirely abstracted from "real life" contexts (Mason, 2005). Such an inquiry also permits the researcher to incorporate participants' actual expression of matters from their own perspective by their own words.

Apart from such deliberation, qualitative approach is best suited for gender based inquires as it enables the researcher to discover the implication of underlying social differences and similarities between men and women in their social contexts. As a feminist researcher Shulamit Reinharz (1992) asserted that "qualitative approach produces non standardized information that allows the researcher to make full use of differences among people and it shows a valuable reflection of reality.

Quantitative approach (i.e. questionnaire) is employed for the purpose of triangulation that increases the validity and reliability of the research. Moreover, the questionnaire is intended to provide broader base to the study about challenges and opportunities that are mentioned by relatively few participants in the qualitative study. To this effect, the questionnaire is designed to measure pre identified challenges of adherence, monitoring health status, nutrition, drug and alcohol use and safer sexual practices among sampled men and women.

### **3.2 Research Setting**

According to MOH/HAPCO report, as of October, 2007 there are 272 ART provision sites all over Ethiopia. Out of these total 46 (34 public and 12 private) sites are found in Addis Ababa. These sites are serving a total number of 47, 770 individuals out of the total 109,552 persons on ART in Ethiopia.

Among the 46 sites in Addis Ababa, Zewditu Memorial Hospital was selected purposefully for this study because of two main reasons. First, the hospital is pioneer in dispensing ART service in Ethiopia. In addition, as of the end of November 2007, a

total of 4067 individuals ( 1791 women, 1779 men and 497 children) have been attending ART service in this hospital and this number is increasing from time to time. Everyday on average 5 individuals start ART in this hospital. In fact, the hospital is serving the highest number of ART users than any other sites in Ethiopia.

Secondly, according to the director of the ART clinic at Zewditu hospital, most of their ART service attendants come from two sub cities (Kaliti/Akaki and Kirkos) which the former sub city is far from the Hospital and the later is characterized by severe poverty, commercial sex work, malnutrition etc . For the reasons mentioned above the hospital was found out to be the appropriate place to meet the targets of this study.

### **3.3 Participants of the Study**

The participants of this study are ART service users both men and women at Zewditu Memorial hospital who have been living with ART for more than 6 months. Six months are set as minimum period because (WHO, 2003) defines this period is when the short term drug side effects go away and better life adjustments with the drugs are made by most people taking ART. Hence, it is believed to be easy to identify challenges and opportunities faced by the participants in the study.

In addition, all of the participants were greater than 14 years old. Fourteen years is set as per the Minister of Health classification of ART users that considers all who are above 14 years old as adult ART users. A total of 274 (137 men and 137 women) participated in interview, focus group and survey. Moreover, two (one Adherence counselor and one ART nurse) participated in the study because it is believed that they have clear understanding of problems faced by ART users.

### **3.4 Procedures of Data Collection**

Prior to the collection of the actual data in the field, I submitted four copies of my proposal to Addis Ababa Regional Health Bureau in order to have ethical clearance. After the ethical review committee at AARHB completed reviewing the proposal a

letter was written to Zewditu Memorial Hospital administration so that I could have access to information both from the ART users and providers right at the hospital.

After getting the approval of the medical director, pilot interviews were conducted among four interviewees (two female and two male) and corrections were made on the sequences and clarity of questions. The actual data collection took place from March 10- April 5, 2008. The first week was dedicated to in depth interview and focus group discussions and the later week was distributing the questionnaires. The interviews were conducted solely by the researcher and the researcher also guided the three focus group discussions held for three consecutive days.

However, four (two male and two female) enumerators were purposefully employed to administer survey questionnaires. This was done in order to increase participants' comfort in which the male enumerator was collecting data from male respondents and the female enumerator from female respondents.

### **3.5 Method of Entry**

Negotiating entry to the participants' private information was not an easy task; it was made possible because of two main enabling conditions. First the hospital's waiting room was found out to be a strategic place where people from different walks of life having the same HIV status come together. The researcher witnessed that this place is the usual experience sharing floor for many of them to discuss issues related to their medications and other social matters. Hence it turned out to be easy for the researcher to approach interview and survey participants just by explaining the purpose of the study. Most of them volunteered to take part in the study and explained that had it not been at this place they will not be willing to talk about their medications.

Secondly, the ART clinic administration allowed the researcher to use a small private room found just in front of the waiting area. This allowed keeping privacy and confidentiality of participants in interview and focus group discussion. Moreover, the

adherence counselor and ART nurse helped the researcher a lot in convincing and recruiting participants.

Despite of such helpful conditions, there were also individuals who refused to take part in the study. Some of the reasons they mentioned include ill health conditions, lack of time and some have already participated in similar studies and become reluctant. In addition, few well to do men and women told that the objective of the research does not concern them.

### **3.6 Instruments of Data Collection**

For the purpose of collecting data, both qualitative and quantitative tools were employed; the tools were in-depth interview, focus group discussion and questionnaire. The detailed justification and use of these tools presented as follows.

#### **3.6.1 In- depth Interview**

In-depth interview or unstructured interview was employed as the major source of data collection for this study. The need to rely on in-depth interviews as major form of data collection arises from the exceptional interactive nature of the instrument that gives much opportunity for the researcher to probe deep into the interviewees' personal experiences. Furthermore, it is a useful approach that helps best to capture women's challenges while comparing their differences with men.

Accordingly, fourteen individuals (7 women and 7 Men) were purposefully selected based on the following criterions that include living with HIV treatment drugs for more than 6 months and above fourteen years old. All interview participants were randomly approached when they come to Zewditu Memorial Hospital for drug refill and health checkups. They were interviewed by the researcher at the small room provided by the hospital.

Twelve guiding questions were prepared so as to guide the interaction between the researcher and the interviewee. The questions presented to the interviewees include

introduction about their personal biography, starting date of ART, challenges they faced regarding meeting the requirements associated with ART which include adherence, nutrition, monitoring health status, alcohol and drug use and practicing safe sex. They were also asked about how their culturally assigned gender roles shed light on their life with ART. Finally, they were asked to identify opportunities that have improved their life with ART.

In addition, two key informant interviews were conducted with (one Adherence counselor and one ART nurse). They were asked what kinds of socio cultural and economic challenges their clients usually mention. The purpose of including such interviews is that since both of them have daily contact with ART users they have knowledge of patterns and kinds of problems and opportunities encountered by ART users. In all interview sessions, tape recorder was used after permission was gained from the interviewees. Otherwise all of the answers were written by note.

### **3.6.2 Focus Group Discussions**

Focus group discussion was the second major tool of data collection employed for this study. The purpose of using this tool was that it enables to collect a variety of ideas on a particular issue as well as allowing interaction between participants so that it intensifies the probability of getting quality and diverse information. Accordingly, three focus group discussions were conducted on three consecutive days. Two of the focus group discussions were organized among a group of men and women separately, each group consisted of six individuals. Moreover, one focus group discussion was conducted by mixing men and women that enabled the researcher to explore dimensions of similarities and differences on a particular issue raised.

The discussants were selected based on their use of ART for more than six months, age and their willingness to participate in the discussion. All of them were approached as they come to take their monthly pills at Zewditu Memorial hospital ART clinic.

The discussions were guided by seven questions that focused on basic challenges ART users encounter on adherence, nutrition, monitoring health status, alcohol and Khat use and safer sexual practices. They were also asked to discuss how the socially constructed gender roles have implications over their use of ART. In addition, participants were asked to identify existing opportunities in relation to their use of ART. In all the discussions, the researcher took the role of guiding the discussions according to the research objectives and there was also one rapport to take note. Tape recorder was used to keep the audio information for later transcription.

### **3.6.3 Questionnaire**

As stated before, survey questionnaires were employed to corroborate the qualitative information gained through in depth interviews and focus group discussions. Thus, interviewer administered questionnaires were distributed with the help of four enumerators (two female and two male). A total of 240 (120 women and 120 men) ART users who have been living with treatment drugs for more than 6 months and greater than 14 years old were contacted randomly as they come to take their monthly pills at Zewditu Hospital. Among the questionnaires distributed, all of them filled except some responses were missing.

Survey questions were prepared after in-depth interviews and focus group discussions were completed. This is because it was based on some pre identified patterns of responses survey participants were measured. Survey questions were first written in English, translated in to Amharic and then translated back to English to ensure accuracy and consistency of wording.

The sections of the questionnaire was divided in to two parts the first part addressed respondents' socio-economic and demographic background. The second part dealt with respondents' experiences of poverty, fear of stigma and gender based violence as challenges of adherence and time and cost challenges as obstacles of monitoring health status. In addition, respondents were asked their challenges related to norms surrounding food intake. They were also asked if they take alcohol and Khat or quit

such addictions because of starting ART. Questions on challenges of safer sexual practices were not included in the survey as sexuality is a sensitive issue. Finally, respondents' were asked their responses about identified opportunities that help their life with ART. Most of the questions were designed at the two point scale "yes" and "No".

### **3.6.3.1 Sampling Procedures**

For the selection of survey respondents, 2 sampling techniques were employed

#### **Flow population sampling frame**

Flow population samples are generated by approaching people in a particular location or setting when they flow to get a certain service (Blaikie, 2003). For this study, samples are drawn from Zewditu Memorial Hospital's ART clinic when users flow to get ART service. A total of 240 ART users were approached during two weeks time. To determine the sample size the statistical consensus on drawing 10% of the population was adopted. For details see appendix V.

#### **Stratified Random sampling method**

The target population was first stratified by sex (male/female) and randomly approached and equal number of men and women included in the study if they have lived with ART for more than 6 months and above 14 years old.

## **3.7 Ethical Considerations**

As mentioned earlier, the AAHB ethical review committee evaluated the research proposal including the objectives and contents of the questionnaires. The Bureau also issued ethical clearance. Accordingly, all the necessary precautions including time, conveniences and opt out options were considered. Data collection continued after introducing the participants with the research objectives and proceeded after

gaining their informed consent verbally. Participants were invited to a small room that ensures their privacy and confidentiality.

### **3.8 Data Analysis**

Both qualitative and quantitative data analysis techniques were employed in this study. The qualitative data collected through in-depth interviews and focus group discussions was first transcribed and translated from Amharic to English day by day after each interview and discussion were over. After deep reading of the qualitative data, themes of analysis that fit to each pre-identified categories were selected. These pre-identified categories were determined based on the WHO definition of requirements of ART use. Under each of these categories information from in-depth interviews and focus group was merged and cases were prepared for the purpose of thematic analysis.

With regard to the quantitative data, Microsoft excel program was used to calculate frequencies and percentages to all questions. Quantitative data entered in to the computer after open-ended questions were coded and edited. Finally, data from interviews, focus group and survey were integrated and an in-depth analysis and interpretation was made based on each of the pre-identified categories.

## **4. FINDINGS AND DISCUSSION**

This section is organized in such a way that first it introduces the background characteristics of participants in the interview, focus group and survey. The aim of describing the background of the participants is in order to introduce the reader about whom the study is referring to. Then proceeds to the discussion of findings under five pre-identified categories that include adherence, nutrition, monitoring health status, alcohol and Khat use and safer sexual practices.

### **4.1 Background Characteristics of Interview Participants**

A total of fourteen (7 men and 7 women) ART users were interviewed. Accordingly, the age range of the participants was 24-50 years for women and 33- 56 years for men. Out of the seven women interviewed, four were between 34- 40 years old and one woman was 51 years old and the youngest of all was 24 years old. In the case of men interviewees, out of the total seven interviewed two were above 50 years old and the rest five were between 32-45 years old.

With regard to how long they have been living with ART, out of the seven women, three lived with ART for two and above years while the rest four lived between a year and eight months. In the same manner, out of the seven men, three lived with ART for two and above years, the rest lived between a year and nine months. (See table 1 and 2)

The marital status of interviewees shows three women were married, two were widowed and two were single. In the case of men two were married, three were widowers and one was single.

Education wise, out of the seven women interviewed, three were illiterate, one had elementary education and three completed high school studies. While out of the seven men interviewed, three were illiterate, three completed high school and one had diploma.

Only one of the women interviewees had formal employment. One was dependant on families' assistance, two by their husband's income, one was a daily laborer, one was a street vendor and the last one was housemaid. Out of the seven male participants, four had formal employment, one was a daily laborer, one generates income by renting houses and one was dependant on family assistance. Three of the woman and two of the men had one up to three dependant children while the rest did not have children. Table 1 summarizes the background characteristics of interview participants.

**Table 1. Background Characteristics of Interviewees**

Sex	*	Age	Time since ART started	Level of education	Marital status	No of children	Means of income	Housing condition
Women	K	36	2yrs 3 month	Elementary	Married	1	Daily laborer	Rent
	L	50	3yrs 6 month	Secondary	Widowed	3	Family assistance	Own
	T	35	1yr	Secondary	Single	-	Gov't employee	Family
	W	24	2yrs	Secondary	Married	1	Husband's income	Rent
	M	38	1yr 8months	Illiterate	Single	-	Housemaid	-
	S	28	1yr	Illiterate	Married	1	Husband's income	Family
	Y	34	8 months	Illiterate	Single	1	Street vendor	Rent
Men	A	45	9 month	Illiterate	Widower	2	Family assistance	Family
	B	34	1yr 2 month	Secondary	Widower	1	Gov't employee	Rent
	H	33	3 yr 4month	Diploma	Single	-	Pvt company employee	Rent
	C	56	2 yr 5 month	Illiterate	Widower	3	Rent houses	Own
	D	54	1yr 6 month	Secondary	Married	-	Gov't employee	Rent
	R	32	1 year	Secondary	Married	1	Gov't employee	Family
	Z	42	2 yrs	Illiterate	Single	-	Daily laborer	Family

\* Pseudonym

## **4.2 Background Characteristics of Focus Group Discussants**

Focus group discussion was the second major tool of data collection employed in this study. A total of 20 (10 male and 10 female) participants involved in three focus group discussions held for three consecutive days. The first and second focus group discussions were held among men and women separately each group consisting of six individuals while the last discussion was held by mixing four women and four men. All of them were contacted at Zewditu hospital ART clinic, discussions were also held right in front of the waiting room.

In the first two separate FGDs, the age range of participants for women was 27-53 and for men 29-45. The educational background of participants shows that three women and two men had primary level education and one woman and three men had secondary level education. One woman able to read and write and one woman was illiterate.

Regarding participants' marital status, three women and two men were widowers, one woman and three men were single, one man and one woman were married.

As to the participants' means of income, two women live on family assistance and the rest four generate their own income working as housemaids, waitress and by selling Injera and washing cloths. While out of the six men interviewed, two were government employee, two were guards and one was dry waste collector. Their housing condition shows the majority (four women and three men) live in rented houses either from Kebele or private. Table 2 and 3 describes the background characteristics of FGD participants.

**Table 2. Background Characteristics of Focus group Participants**

<b>Sex</b>	<b>*</b>	<b>Age</b>	<b>Time since ART started</b>	<b>Education level</b>	<b>Marital status</b>	<b>No of children</b>	<b>Means of income</b>	<b>Housing condition</b>
<b>Women</b>	E	27	2 yrs	Primary	Single	-	Family assistance	Rent
	F	32	8 month	Primary	Divorced	1	Washing cloths	Rent
	G	42	2 yrs	Read & write	Widowed	3	selling Injera	Rent
	I	34	2 yrs	Secondary	Single	2	Family assistance	Family
	J	53	4 yrs	Illiterate	Widowed	1	Housemaid	-
	N	28	1 yr	Primary	Married	2	Waitress	Rent
<b>Men</b>	O	36	3 yrs	Primary	Single	-	Mini shop	Own
	P	40	3 yrs	Secondary	Widower	1	Guard	Rent
	Q	32	3 yrs	Primary	Widower	1	Guard	Rent
	U	29	2 yrs	Secondary	Single	-	Gov't employee	Family
	X	45	1 yr	Secondary	Married	2	Dry Waste collector	Rent
	Y	38	10 months	Secondary	Single	-	Gov't employee	Family

\* Pseudonym

In mixed sex focus group discussion, only one man was over 50 years old and two women and two men between the 30-40 years old while one woman was below 30 years old. Education wise, two women and two men had completed secondary level and one woman and two men had primary level education and one woman was illiterate.

The marital status of discussants shows that two women and one man were married. One woman and two men were single. In addition one man and one woman were widowed/er. Three of the women had one or more child and out of the male participants two had children.

With regard to their means of income, one woman and two men had formal employment. Two women were dependent on family assistance and husband's income and one woman was waitress. One man had a mini shop and one was a guard. Their housing condition indicates that two women and three men live in rented houses; one man and one woman have had their own house and one woman live with her families. Table 3 shows the background characteristics of mixed sex focus group discussants.

**Table 3. Background Characteristics of FGD participants (Mixed Sex)**

	*	Age	Time since ART started	Educational le	Marital status	No of children	Means of income	Housing Condition
<b>Women</b>	PL	41	1 yr	Secondary	Married	1	Gov't employee	Rent
	ZT	47	11 months	Primary	Single	-	Waitress	Rent
	AB	32	2 years	Illiterate	Married	-	Husband's income	Own
	HA	28	2 yrs	Secondary	Widowed	2	Family assistance	Family
<b>Men</b>	AT	47	3 yrs	Primary	Widower	1	Guard	Rent
	PQ	49	2 yrs	Secondary	Single	-	Gov't employee	Rent
	SL	37	10 months	Primary	Single	-	Mini shop	Rent
	KM	53	2 yrs	Secondary	Married	2	Prvt comp employee	Own

\* Pseudonym

### **4.3 Background Characteristics of Survey Respondents**

Survey questionnaires were distributed among 120 men and 120 women ART users at Zewditu Memorial hospital. Regarding the age composition of respondents, in both men and women group the majority fell with in 35-44 years old. There were equal number of men and women with in age range of 14-23 accounting 5.8 % of respondents. However, there are more number of women 33.3% than men 18% within 24-34 age group. And in reverse there are more men 25% aged over 45 than

women 12.5%. This shows that most of the participants are at their productive and reproductive ages.

The educational level of respondents is concurrent to the national figure that shows gender disparity, 30% of women are illiterate as compared to 16.7% men and only 8.3% women have had higher education (mostly diploma) than 15% men. Regarding respondent's marital status, 42.4% men and 38.3% women are currently married, 24.2% men and 11.7% women are widowers/ed. Moreover, 6.7% men and 16.7% women were divorced. 60.8% men and 65% women have one or more children. (See table 4)

The occupational profile of respondents shows gender disparity in that 14.2% women have formal employment as compared to 21.7 % men. Besides, 34.9% women and 18.1 % men live on family assistance, the rest of the respondents generate their own income through different informal means. Moreover, relatively more number of men 38.9% respondents earn average monthly income range of 301-600 birr. While the majority of women respondents 56.9 % earn average monthly income below 300 birr. (See table 5)

#### **Table 4. Background Characteristics of Survey Respondents**

		Male		Female	
	Level	Freq	Percentage	Freq	Percentage
<b>Age</b>	14-23	7	5.83	7	5.83
	24-34	22	18.33	40	33.33
	35-44	61	50.83	58	48.33
	Over 45	30	25.00	15	12.50
	<b>Total</b>	<b>120</b>	<b>100</b>	<b>120</b>	<b>100</b>
<b>Education</b>	Illiterate	18	16.36	36	30.00
	Read and write	24	20.33	17	14.16
	Primary (1-8)	33	27.95	38	31.66
	Secondary (9-12)	25	21.18	19	15.83
	Higher education diploma, degree	18	15.25	10	8.33
	<b>Total</b>	<b>118*</b>	<b>100</b>	<b>120</b>	<b>100</b>
<b>Marital status</b>	Never married	24	20.00	30	25.00
	Currently married	51	42.50	46	38.33
	Have boy/girl friend	8	6.66	10	8.33
	Widowed/ widower	29	24.16	14	11.66
	Divorced	8	6.66	20	16.66
	<b>Total</b>	<b>120</b>	<b>100</b>	<b>120</b>	<b>100</b>
<b>Do you have Children?</b>	Yes	73	60.83	75	64.10
	No	47	39.16	42	35.89
	<b>Total</b>	<b>120</b>	<b>100</b>	<b>117*</b>	<b>100</b>
<b>Number of children</b>	One	32	45.71	25	32.05
	Two	28	40.00	27	34.61
	Three and above	10	14.28	26	33.33
	<b>Total</b>	<b>70*</b>	<b>100</b>	<b>78</b>	<b>100</b>

\*Missing responses

**Table 5. Employment, Income and Housing Conditions of Respondents**

	Level	Male		Female	
		Freq	Percent	Freq	Percent
<b>Formal employment</b>	Yes	26	21.66	17	14.16
	No	94	78.33	103	85.83
	<b>Total</b>	<b>120</b>	<b>100</b>	<b>120</b>	<b>100</b>
<b>Source of income for formally unemployed</b>	Trade (petty, mini shop, higher shop)	16	17.02	11	10.67
	Street vendor	7	7.44	11	10.67
	Daily laborer	6	6.38	7	6.79
	Drivers (taxi, heavy truck)	17	18.08	-	-
	Guard	9	9.57	-	-
	Housemaids, waiter/ress	5	5.31	10	9.70
	Family/neighbors assistance	17	18.08	36	34.95
	Husband/wife income	2	2.12	16	15.53
	Assistance from NGOs	4	4.25	5	4.85
	Other (pension, renting houses)	11	11.70	7	6.79
	<b>Total</b>	<b>94</b>	<b>100</b>	<b>103</b>	<b>100</b>
<b>Average monthly income</b>	0-300	26	27.36	41	56.94
	301- 600	37	38.94	18	25.00
	601-900	19	20.00	6	8.33
	901+	13	13.68	7	9.72
	<b>Total</b>	<b>95*</b>	<b>100</b>	<b>72*</b>	<b>100</b>
<b>Housing condition</b>	Private	25	21.36	12	10.00
	Rented from private	39	33.33	26	21.66
	Rented from Kebele	27	23.07	48	40.00
	Family/relatives house	18	15.38	25	20.83
	Other	8	6.83	9	7.50
	<b>Total</b>	<b>117*</b>	<b>100</b>	<b>120</b>	<b>100</b>

\* Missing responses

#### 4. 4 Discussion

#### **4.4.1 Adherence**

Most people on ART take 4 pills on average twice a day. They often take additional drugs to prevent and treat opportunistic infections. Rigorous adherence is crucial for ART to be effective in suppressing the viral replication and to prevent emergence of drug resistant HIV. To this effect, ART must be taken at the right time, the right dose and by fulfilling needs and restrictions associated with each type of drug regimens.

Adherence is not a one time issue but it is a life time, dynamic and complex process influenced by an interrelated internal (psychological and physiological) and external (socio cultural and economic) factors circumscribing the patient. “Every day with every dose users must navigate through influences that bear upon their simple act of taking a medication. And in fact this navigation must take place day after day, doses after doses, ad infinitum” (American Public Health Association, 2003). In this study, socio-cultural and economic factors that influence adherence are identified and discussed from gender perspective.

Although reports of missing doses are very rare among participants, it is important to remember that non adherence encompasses missing and mixing doses, not keeping appropriate time intervals and unable to follow up food and fluid restrictions.

The socio-cultural and economic factors that are found to influence adherence among men and women in this study are poverty, gender based violence and fear of stigma. Though some of these problems are commonly shared by both men and women, their extents vary and an attempt was made to substantiate extents using survey results. Moreover, it is important to note that the identified factors are not the only factors that influence adherence.

#### ***Poverty and adherence***

Multiple facets of poverty have imposed varieties of challenges to maintain best levels of adherence among men and women taking ART. Poverty in terms of lack of independent income, food and housing and lack of adequate treatment information are identified as the basic problems of non adherence in this study. Though both men and women experience poverty, the intensity varies because of the historical and existing social and economic inequalities as well as with the prevalent gender norms and behaviors. Moreover, the UNIFEM 2006 report also indicated that, women living with HIV have higher rates of poverty than men with HIV.

Both the qualitative and quantitative findings showed that lack of independent and regular source of income is creating a major problem to fulfill the food and fluid requirements of ART. Consequently, it is a great challenge for many poor women and men to get access to adequate amount of food and a glass of clean water at specific times of the day on regular basis. As a result, they are obliged to take their medications later or earlier than the prescribed times either empty stomach or with very little amount of food.

In urban setting where access to food is primarily determined by better income; without consistent source of income it is difficult to secure enough amount of food and be able to correctly maintain the regular drug intake time. Women's access to better income has been constrained by multiple social, cultural and economic pressures they have gone through including conditions that exposed them to HIV. Compared to men, women lack access to better education, right over resources, are heavily burdened with household responsibilities and represent the majority who are infected and affected by HIV. The snowball effect of such disadvantages obviously influences their adherence to treatment.

Qualitative data shows that women who are uneducated, unemployed and dependant on their husbands' income fall in great difficulties to adhere to their treatment particularly when the husband died first. Beyond the overall household

crisis they would unlikely be able to adhere to their treatment. An interviewee said:

My husband was the only income earner to our family; he passed away before free ART was available. For a year, I survived by the money he left but the money was over and neither I am educated nor born to the rich family I was forced to give our two children to their grand parents. Now, I am alone taking ART living with relatives who are also poor... Well my life with ART is very difficult I am not taking the drugs as exactly as I am told ...I don't have a penny at my hand except waiting the meal times of the family and take my drugs later. I lost my hope I cry day and night for my kids if I have my own income I would have raised them. (L, Age 50)

Her condition shows that women's lack of economic resource has severe impact on their treatment adherence and because of this poor women are not in a position to enjoy prolonged and quality of life that is made possible by their use of ART.

Although it is difficult to generalize, it is rarely in our society for a husband to depend on his wife income, so long as he is a bread winner he has increased chance to survive the economic hardship upon the death of his wife. In this case, men's adherence might not be constrained by lack of income but by his small income and dependence on his wife's labor as she was the one to prepare meals and care for the children. A male interviewee said:

My wife died before ART was available; upon her death, my life entered in to crisis as to how I take care of our daughter, how I feed myself. After many ups and downs the problem grew worse when I start ART that always needs food at specific hours of a day. My income is not that much enough to employ a housemaid or always afford hotel meals. I am trapped in such problems and these conditions are affecting my adherence. (B, Age 34)

Even women who are able to generate their own income, their income tend to be small and inconsistent. As the conditions of participants in the survey indicate most of them are street vendors, housemaids and daily laborers whose average monthly income is below 300 birr. This has implication over their regular adherence. As discussants disclosed that there are many occasions they take their

medications after eating a fistful Kollo<sup>1</sup> and a piece of bread once or twice a day. There are also many days drugs are taken empty stomach. An interviewee said:

I sell different types of spices by the road side. There are days I can not even get a birr and in such days, I really hate taking my medications since I won't have anything to eat. Sometimes I look for food in my friends' house and until I got it my drug taking time passes. (Y, Age34)

Her experience tells that because of variable income, the adherence condition becomes irregular. The quantitative data shows that only 14.2% women have formal employment in contrast with 21.7% men. This entails that the majority of women and men living with HIV treatment drugs lack regular source of income that clearly interfere with in the course of their adherence.

A better income also determines one's ability to live in a private home. Lack of private home is mentioned as another factor influencing regular adherence. When both lack of income and private home merges together it really becomes difficult to properly adhere to treatment. A woman described her situation as follows;

I live with my 4 relatives in Kebele<sup>2</sup> owned single room... imagine how can I always prepare my own food at certain specific hours of a day? There is no space at all even to keep my medication safe. For this reason, I take my medications whenever I feel comfortable. (Y, Age 34)

From her words, it is possible to see that lack of housing may hinder one from maintaining optimal adherence. The survey result also shows only 10% women have private home as compared to 20.9% men. Moreover, lack of private home is related to the issue of privacy to store drugs and it is found out to be a paramount concern for those participants who live with families and relatives without disclosing their status. The survey result confirmed that 23% women and 12% men live with families and relatives without disclosing their status.

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<sup>1</sup> A snack made of different roasted grains for example barely, wheat, peas etc.

<sup>2</sup> Kebele is the smallest administrative unit of the local government structure in Ethiopia

Knowledge and access to appropriate treatment information about what treatment is, how it is likely to help, the importance of not missing a single dose or passing specific times affects adherence (Stewart, Padarath & Bamford, 2004). Indeed one of the limitations of ART service in Ethiopia is the lack of adequate treatment information and on going adherence counseling. With in this general context, data from the interview and focus group discussions revealed that men from different social and economic backgrounds are more enlightened and know more about the value of strict adherence. While women particularly poor, uneducated and older women are in great difficulties to properly follow drug regimens. This is confirmed by the adherence counselor as follows;

Many poor older women who are uneducated, having children and many kinds of familial responsibilities come to me by finishing their pills before the actual time given to them. This is because they sometimes mix doses. There are certain types of pills that should be taken once daily but they mix it with others and take it twice. And, sometimes, after skipping morning doses, they take whole day treatment once. These cases are very much serious among those who take other types of medications for co infections like TB. Generally, they do not know purposes of taking each type of medications... This is not really common among men since the day I began working here (about 2 years) very few men came with this problem.

Focus group discussants also informed that women are also more susceptible and influenced by myths and misinformation about ART which could affect their adherence. Although it is difficult to generalize, the fact that women are less educated and unemployed it is usual for them to attend coffee ceremonies in their villages which is the usual place of exchanging right and wrong information related to ART. An interviewee told her experience as follows;

In my new village, it becomes usual to discuss about HIV during coffee ceremonies. My new neighbors did not know that I am living with ART. I hear them saying all the negatives about ART, exaggerating side effects that it is very toxic and destroys liver and it is better to die than live with

it. I fear when I came back home and there were days I did not take my medications until I asked my doctor about what I heard. (L, Age 50)

From her experience it is visible that the lack of appropriate information about ART among the society in general could possibly affect treatment adherence.

Moreover, quantitative data shows the limited places women and men can access ART related information has also a contribution in influencing their adherence. Table 6 shows from where ART users get information related to their medication. Accordingly for women, the major sources of ART related information are short stay with doctor (99%) and the informal discussion at the waiting room (70%) and media (20%). However, the first two events rarely happen either once in each month or every three months that clearly is not enough to reinforce adherence. Though the situation is the same for men relatively more men are able to access ART related information from print and electronic media and PLHIV associations. This can help them to improve their adherence much better than women.

Furthermore, the informal discussions at the waiting room could also be sources and means of spread of misinformation about the efficacy of ART. This was witnessed by the researcher herself during data collection process. A participant also explained her experience like the following;

It was during the first month I started ART, I was ravaged by sores and I came to hospital and while I was waiting my turn another woman sat behind me. We began discussing issues and she told me that she had the same problem when she started ART but got better after taking the (pink types of pills). She gave me some of the pink ones as she was about to return it. Though I met the doctor on that day I was told to continue taking what I have started already. But I took what she gave me. (M, Age 38)

Such experiences clearly indicate that how lack of appropriate treatment information may lead to complicated health risks. The feminist concerns raised in this regard found to be true in such a way that women have relative disadvantage to access sufficient information about ART and this clearly has implication over

their health. The following table in general shows respondents' source of ART related information.

**Table 6. Respondents' sources of ART related information**

Sources of ART related information	Men		Women	
	Yes %	No %	Yes%	No%
Hospital Doctor/ nurse ( a short stay)	98	2	99	1
Hospital waiting room (Informal discussion)	60	40	70	30
Media/ News letter , magazines, radio, TV	50	50	20	70
PLHIV associations	20	80	10	90
Other	3	-	1	-

All in all, poverty in any of its dimension can influences the adherence condition of men and women on ART. However, poverty disproportionately affects women, their relative disadvantages in terms of lack of consistent source of income, private home and appropriate treatment information affected their adherence. Moreover, discussants informed that the face of poverty and the need to adhere to treatment is pushing young poor women towards commercial sex work. Studies consistently have shown that poverty is one of the major reasons why women practice commercial sex work and in the new era of HIV the situation has continued the same. As a woman discussant said:

In our village, poor young girls who recovered from their bed ridden situation because of ART has began or continued commercial sex work, as they do not have other means to fulfill the requirements of ART. Some of them changed their residence to other areas where no one could identify them... I tell you this has become the new fashion since the availability of free ART. (G, Age 42).

From such testimonials it is possible to notice that the burden of adherence is pushing women to risky situations, where they might not be able to distant themselves from re- infection and giving the drug acquainted virus to clients who refuse to use condoms. Thus, the challenges of poverty and adherence are a bit complicated in women's life than men.

### ***Fear of Stigma and discrimination***

Data from focus group and interview indicate that both men and women on ART fear stigma and discrimination in different contexts depending on where the individual is situated and whether his/her HIV status is disclosed or not. This fear is found out to have a profound impact on their adherence to their treatments. Findings showed that both men and women are uncomfortable to take their medication in the presence of other people who do not know their status. Even status is known privacy is sought in many contexts. Because of this, there were times they preferred to skip doses or take earlier or later than the prescribed times.

Stigma is feared because of the negative reactions associated with it. Such reactions include rejection by partner, social exclusion, loss of employment, denial of self advancement opportunities, threat of violence etc. Women fear such consequences in much broader ways than men. It is because they have low socio economic status; found subordinated either to their husbands or families it is unlikely for them to bear such costs. Thus, fear of stigma means the decision to disclose status is always a fraught in danger. This in turn, complicates one's ability to take medications properly and difficulties become severe if status is not disclosed to persons whom they are living with.

In this regard, the role of family is pivotal in supporting treatment adherence and that is why status disclosure to at least one family member is one of the eligibility criterion to start ART in Ethiopian context. However, qualitative findings showed that there are men and women who live with their families with out disclosing their status for different reasons. The following quotes below attest this fact;

I prefer hiding my status and take my drugs secretly if I disclosed my status I know my relatives would stigmatize me or chase me out of home. I have no where to go even for a single day or a job to sustain my self. Hence, everyday I look for strategic places not to be seen taking my

medications and a place to hide the container. I prefer to live like this than disclosing my status and further complicate my living condition. (HA, Age 28)

A male discussant also said:

My family did not know my status. Everyday, I am in trouble to take my medications on time. I am very careful not to be seen by members of my family. If my family knows my status it would be a great shame for me and to the whole family. It would be better for me to take my drugs irregularly than to shoulder all that shame I brought to my father and mother. (SL, Age 37)

Moreover, discussants informed that there are women who did not disclose their status to their husbands for fear of violence and expulsion from home. In general, at family level, women's treatment adherence is compromised by fear of expulsion by (family and husbands) and shame while men fear only shame not expulsion or violence like women do. Quantitative data also support 39% women as compared to 28% men fear taking their medications in front of their family members. See table 7

Fear of stigma at work places is affecting the adherence condition of men and women depending on the nature of their working environment. Those who work in shifts at factories, pastries and hotels have problems of keeping appropriate time frequencies fearing stigma. Since their working hours are not usually fixed drug taking times may not fit to their daily routine. As a male discussant said:

I am a guard at one private company, I do not want to take my medication in front of my colleagues and there are days I take late hours and in some other days I swallow it using my saliva. One day, I remember the pill remained at my throat and I was constantly coughing when people arrived and offered help. (P, Age 40)

A young woman who is waitress described her difficulties as follows;

I am waitress in a café; we work in shift, since I do not want to take my medication in front of my colleagues every other day I take it earlier than the actual time before going to my work place. (N, Age 28)

Fear of stigma is severe among those women who work as housemaid as their adherence is always challenged by the need to hide their status from their

employers and taking their medications properly. An interviewee who works as housemaid said:

I am always in difficulties to take my medications properly; I have to be careful not to be seen by any of the family members. Particularly in the mornings, I take it with out food and other time while waiting breakfast I take after certain hours passed ... If my status is known I know I will lose my job. (M, Age 38)

From their experience it is visible that fear of stigma is internalized and so deep affecting conditions of adherence. Table 7 below shows survey respondents' experience of fear of stigma affecting their adherence at family, community and work place.

**Table7.Respondents'experience fear of stigma affecting their adherence**

Do you fear taking your medication in following places, situations?	Male		Female	
	Yes %	No %	Yes %	No%
Family (husband, wife, relatives)	28	72	39	61
Community	86.70	10.30	90.20	9.80
Work place	67	33	43.40	56.60

Generally, findings revealed that fear of stigma is influencing men and women treatment adherence in many contexts. However, because of social and economic reasons fear of stigma has additional dimensions for poor women than men.

***Gender based violence and adherence***

Literatures on factors influencing adherence ignored the unique aspect gender based violence has in women's life with ART. Gender based violence is a global phenomena inflicting physical, psychological and sexual harm on women. It is embedded in the context of cultural, socio-economic and political power relations in which male power dominates over women (VSO, 2007).

A recent report by Human right watch in Zambia (2007) was the first to report that women on ART could experience violence/human right abuses related to their ART use. In similar ways, findings in this study showed that in the new era of the HIV epidemic, women's adherence to antiretroviral therapy is constrained by gender based violence and its threat. As the adherence counselor at Zewditu Memorial hospital informed that;

There are women coming to us after they were snatched their medications by their husbands, there are also some more who were expelled from home empty handed with out their drugs. And not few who interrupted ART because their husbands forced them to do so. This is the reality we are witnessing now a day.

A study about the link between HIV positive status and violence by Population Council (2003) revealed that HIV infected women are at the increased risk of intimate partner violence. This becomes more complicated when treatment that needs regular adherence is started.

An interviewee illustrated her case as follows;

I live with my husband who also takes ART. For the reasons I do not know, he is envious about me and he tells me that I am becoming beautiful after I began taking these drugs. We argue a lot and the day before yesterday, he took away my medications and ignored me as if nothing happened. It was Friday night, I could not do anything until Monday and I missed 2 days treatment by now. Today, I am here to explain my case and take refill. I am worried about my life, it is better for me to die than to live like this. (S, Age 28)

The woman's experience tells that violence has far gone beyond the usual emotional, verbal and sexual harms on women to the denial of the life extending treatment drugs. Here, it is important to note that in the context where the world is equating access and use of ART as one of universal human right issues, hindering women from taking medications is a blatant violation of one of their basic human rights.

Female focus group discussants informed that married women are at the increased risk to suffer from ART related violence. Their day to day pill taking action can be obstructed by the violent behaviors and actions of their intimate partners who might have also brought the virus to the family however, the gender dynamics makes them to be blamed as vectors of the disease to their husbands and to their children.

Married women's adherence condition is further obstructed by their economic dependence on their husband's income. Researches have shown that economic dependence is one of the basic reasons for women to stay in a violent relationship. Adding to this fact, findings in this study affirmed that the need to adhere to their treatment has become also an additional cause for women to stay in violent relations. An interviewee whose words mentioned above said:

Neither I have my own income nor do my relatives live in this city. If I left his home, it will be more difficult for me to adhere to my treatment. I chose to endure my husband violent behavior than getting in further complications. (S, Age 28)

Participants in the qualitative study informed that the threat of violence is compelling women to take their medication by hiding themselves even at their most private place (home). This is commonly observed among women on ART whose husbands' have not yet tested and in denial of the will be positive status. Women in this instance are more likely to suffer from an intimidation that has impact on their taking or quitting their medications.

Family violence is other type of violence that interferes in the course of women's adherence. Interviewees and discussants informed that family violence is common among those poor women who live with their relatives by hiding their status. Their constant strive to achieve better adherence could result in status disclosure that could be followed by violence. A female discussant mentioned:

No matter how hard you try to hide your status, people are now becoming aware that if you are experiencing TB, Herbs, skin rushes (opportunistic infections) and if you are taking drugs at certain hours of a day they immediately identify that you are living with HIV. There are women in our villages who are expelled from their relatives home when they are seen taking ART. (G, Age 42)

Housemaids also experience violence in their attempt to maintain adherence. They would be chased out by their employers when discovered that they are living with ART. A participant told her experience like the following;

After my health situation got better because of ART, I decided to continue my work as a housemaid. I was very much careful about taking my drugs at prescribed time and not to be seen while taking it. For about 2 months, no one recognized that I am taking ART. But I did not know that my employer was spying on me. One day, she asked me, but I lied to her that it is a medication for other disease. She was not convinced at all. On the other day, I found her checking my bag and she got the container and recognized it. She insulted me for hiding my status since I used to take care of her child. Finally, she told me to leave her house. (M, Age 38)

Such experience shows that women living with ART experience violence and humiliation not only from male partners but also from women employers. Further to this, studies confirmed that housemaids are also potential victims of sexual violence (Nebyu, 2007; Hana, 2007) in that they have also at the increased risk of re-infection and contracting drug resistant HIV strains. The following table shows female respondents' experience of ART related violence.

**Table 8. Female respondents' experience of ART related violence**

Item	Answer	Freq	Percent
Chased out by family/relative/employers because	Yes	12	10.34

Of HIV status and ART	No	104	89.65
	Total	116*	100
Partner got angry when sees you taking ART	Yes	15	32.60
	No	40	86.95
	Total	46**	100
Snatched your medications by someone	Yes	8	6.66
	No	112	93.33
	Total	120	100
Fearing violence, skipped doses or take medication before prescribed times	Yes	17	14.52
	No	110	94.01
	Total	117*	100
Have the experience of drug interruption because of violence	Yes	14	11.66
	No	115	95.83
	Total	120	100

\* Missing responses

\*\*Women Participants who are currently married

From issues discussed above, women on ART are experiencing violence in a new version in the new era of the HIV epidemic. They are denied of their life prolonging medications by their intimate partners and in their attempt to hide their status while taking ART they become victims of violence. Given the dangerous risks of non adherence, irregular adherence and discontinuation of ART, women again become vulnerable to drug resistance, disease progression and reduced survival because of gender based violence. In this regard, feminist concerns are found to be right in that women's socio-cultural and economic vulnerability to violence have constrained their ability to better meet the requirements of ART.

At last, the availability of post exposure prophylaxis (PEP) is believed to tackle the intersection between sexual violence and HIV. Though it is a ground breaking solution to victims of sexual violence, findings of this study show that the service utilization is not as such satisfactory. According to the adherence counselor at Zewditu hospital, a total of 116 individuals got the service since 2005, out of the total service recipients more than 80% were health professionals. A widespread

lack of information about and availability of PEP and delays in treatment initiation were mentioned as the major reasons why women are not able to benefit from such treatment features.

#### **4.4.2 Nutrition**

Scientists have confirmed that good nutrition enhances the efficacy of ART. Moreover, most types of ARVs are accompanied by certain types of food requirements and restrictions. Some work better with specific nutrients; others require reduced consumption of that nutrient. Sometimes, one ARV needs to be taken with food and one without food, requiring the drugs to be taken at separate times. There is high drug- food interaction among many types of ARVs. All things considered, persons on ART must strictly follow what type of food their regimen needs and what to avoid.

Poverty in general limits the capacity of PLHIV to comply with special food requirements of ART that can result in reduced drug efficacy. Both the qualitative and quantitative data shows that most men and women participants are not in reasonable economic stand to fulfill the on going dietary needs of ART. This entails that they face challenges to access enough amount of food on regular basis. The survey result also confirmed that 77.2% men 86% women believe that they are not fulfilling the nutritional requirements related to their types of regimens because of poverty. On top of this, participants in the qualitative study mentioned that after they started ART, their appetite increased a lot but in a context where there is limited access to food this is one big challenge they are going through on daily basis.

Beyond this general condition, the qualitative data reveals that the existing gender based norms are affecting even eating what is available in the household. Traditional gender roles assign women to prepare and serve food to their family while it is not usual for men to enter in to kitchen and prepare and serve meals.

Such types of gender norms found out to have an implication over the food intake of men on ART. A male interviewee said:

While everything is available at home, it is usually difficult for me to prepare food by my self or to open “Mesob”<sup>3</sup> and serve my self. There are days I take my medication without food until my wife returns home and prepare and serve food. ( D, Age 54)

His word explicitly shows that the gender based socialization has brought impact on men’s food intake, as taking ART uniquely require strict meal schedules it is a challenge for them to get food at specific hours of a day. Quantitative data indicates that 62.5% of men respondents faced such challenges as they do not prepare their own food and 36% do not want to serve themselves even when the food is ready. Discussants in mixed sex group agreed that this condition is particularly worse for single men taking ART while living alone. Therefore, with the soaring food prices and with limited amount of income to afford hotel meals, men on ART are facing additional challenges to meet the food requirements of ART because of their gender.

In a different scenario, the interface between taking ART and low income for single men is becoming a cause of a shift in gender roles. Male focus group discussants informed that while ART requires better food and food prices at hotels are increasing many men are facing difficulties. In order to mitigate the two conditions there are men who began cooking their own food. A discussant explained his experience as follows:

I live alone and I used to eat in different hotels, but hotel meals are small, not tasty and getting expensive time after time. Because of this there were days I skip meal times or left out the food what I paid for. After considering my situation, I decided to cook my own food. During the first few weeks it was difficult ...but now I am getting perfect. (H, 33)

Quantitative data shows that 8.6% of men respondents began cooking their own food after they began taking ART.

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<sup>3</sup> A traditional circular container where Injera is usually kept

Women participants in the above discussed conditions are relatively in a better position as they are able to mix and cook what ever is available at the household. This is clearly spelt out among mixed sex focus group discussants where male participants expressed their relative disadvantage position in preparing and taking food timely. This condition in general implies that gender based norms do not always put women in a disadvantaged position rather women may become beneficiaries of their gender roles in such instances.

However, women as mothers and care takers might give priorities to feed their children, husbands and the sick. As mentioned by female discussants and interview participants, this is commonly observed among poor older mothers with larger family size.

An interviewee said:

I have three children (the last one lives with the virus), my nephew also lives with me. My husband is a pensioner who has not started ART... With his little income, I have the responsibility of feeding all the family members. I have to take also my medications properly. I usually prefer to feed my family first as there is no one for them I do not care whether I eat or not. (L, Age 50)

This shows that because women are culturally trained to care for others, to put the needs and priorities of their family first rather their own, they are at disadvantaged when it comes to their own health and wellbeing in the context of ART. Quantitative data shows that 64.7% women responded affirmatively when asked whether they give food priorities to different family members particularly children while they live with ART. The following table shows respondents' experience of nutrition related challenges.

**Table 9. Respondents experience of nutrition related challenges**

Item	Men		Women	
	Yes %	No %	Yes%	No%

Lack of sufficient access to food	77.20	33.80	86	14
Unable to prepare own food because of “gender socialization”	62.50	38.50	-	
Unable to serve food even when food is ready	36	64	-	
Giving priorities to other family members	-		64.70	35.30

In addition to such kinds of challenges, restrictions related to certain types of foods have become obstacles to many poor people not to eat what is available around and take medications. Some of the restricted foods include tomato, raw meat, milk, banana, garlic, hot chilly etc. and each restriction goes with the type of medications prescribed, for some people there are no restrictions for some others restrictions stretch far. Fulfilling such requirements posed additional challenges to ART users; still poor women are at the forefront to suffer. As a female interviewee said:

Sometimes, when I don't have enough money, uncooked tomato with bread is my usual meal because it is a bit cheap, available and do not require much cost. Since the day I began taking ART I am prohibited from eating tomato. As you can see, ART has brought a restriction to this simple food a poor person like me can afford and now it needs additional cost of buying a lemon to eat tomato. (K, Age 36)

Moreover, female focus group discussants asserted that it is difficult to comply with the restrictions on garlic and hot chilly as these spices are traditionally believed to have powers of healing different diseases. Thus, despite the restrictions, participants reported that they take these foods.

In general, poverty could be the major reason to limit men's and women's access to sufficient food. Further than this, gender based norms have also their own roles to determine the food intake characteristics of men and women on ART. As men fall in difficulties to mix and eat what is available easily while women tend to give priorities to other family members.

#### **4.4.3 Monitoring Health Status**

Receiving a course of antiretroviral treatment requires at least a monthly journey to hospitals to obtain drugs, check CD4 and Viral load status. In addition, drug side effects and the presence of opportunistic infections should also be monitored and treated as early as possible.

Though treatment is provided free, traveling to health care centers requires transportation and time costs. Qualitative data shows that men and women face challenges of covering transportation costs, finding suitable time to travel back and forth and spending few or more hours in the hospital. Those ART users who are poor and live far away from Zewditu hospital are caught up in difficulties to monitor their health status regularly. A female interviewee said:

I live with my relatives in the out skirt of Addis (Akaki area). Since I do not have my own source of income, every month it is a great challenge for me to get 7-8 birr for my transportation to hospital. In some months I did not have a penny at my hand let alone going to health centers every time I got sick. (L, Age 50)

From her words it is possible to see that even though ART is provided free, the indirect costs could hinder women and men from monitoring their health status. Lack of transportation money also can become the cause of missing important appointments and drug refill schedules which can also affect adherence. In the survey, 28% of men and 35% of women respondents informed that they have problems of covering transportation costs to the treatment site.

Participants also disclosed that there are days in which the CD4 count machine at Zewditu Hospital would be out of function and they were required to bring blood test results from other private clinics. This costs about 150 birr, which is not affordable by many poor women and men.

Furthermore, qualitative and quantitative findings show that women's household and community responsibilities are other factors hindering them from monitoring their health status. A discussant described her condition as follows:

My husband is a government employee. We have twins who are 3 years old and my mother-in-law who is old and sick live with us, I am the only one to take care of all. I have to cook food, keep an eye over my children, feed my bed ridden mother-in-law and in fact, properly take my medications. Every month, I face difficulties to go and bring my medication from the hospital, as there is no one to keep my children and my mother-in-law at home. In some cases, I beg my friend who knows my status and if she is busy on that day, I arrange for the next day. (S, Age 28)

Her condition indicates that woman's roles as mother and care taker can limit their ability to monitor their health status and respect drug refill schedules. The survey result also shows that 37.5% women experienced challenges to monitor their health status because of their household responsibilities.

For those men and women participants who have formal and informal type of jobs, the nature of their working condition mentioned to be an obstacle to monitor their health status. Participants who have formal employment and did not disclose their status to their bosses face difficulties to get permission every month to respect drug refill schedules and health checkup appointments. A male interviewee said:

I work in a government bank. Fearing stigma, I did not disclose my status and every month it is not easy to leave my work place with out the permission of my boss and it is difficult to ask permission every month without any plausible reason. In some conditions, I passed days; in another I endured my boss anger for the sake respecting drug refill schedules. (R, Age 32)

The survey result shows out of 26.7% men and 14.2% women respondents who have formal employment, 17 % men and 11% women faced challenges to monitor their health status due to lack of permission from work places.

Housemaids are also in difficulty to monitor their health status. They usually do not want to disclose their status fearing the consequences of stigma; thus it is unlikely for them to be able to monitor their health status regularly. An interviewee said:

Being a housemaid, I am not allowed to go away from home every time I want. My rest time is once in a month on Saturdays and Sundays. On these days, hospitals do not give services. Thus in order to bring my medications, I have to produce different reasons or take risks of going to hospital with out the permission of my employer. This is my real problem every month, in most cases; I passed days for the drug refill. (M, 38).

The cost of time spent in treatment centers as well as traveling back and forth can also interfere in day to day income generating activities of men and women. Qualitative data shows that the need to earn to cover daily expenses can prevent one from monitoring health status. Because time away from work means loosing income of the day that possibly determine the household food intake in general. A woman who is street vendor illustrated her condition as follows;

Every month, I face trouble to go to hospital and bring my treatment drugs. It takes half or full day to go and come back. This means that I do not earn income on that day. It affects me and my daughter a lot since we live in hand to mouth situation. (Y, Age 36)

A male interviewee who runs a mini shop also said:

Every month, I have to close my shop either to go and bring my medications or attend health checkups. In such days, I do not earn income to contribute my share in the daily saving association “equib”<sup>4</sup>

From such experiences, though the level varies it is visible that the need to earn income could be a challenge to monitor health status and it can even lead to irregular adherence. The survey result also shows that out of those 45% men and

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<sup>4</sup> Traditional money saving association in which people contribute equal amount of money and receive their cumulative share turn by turn.

31.7% women in the informal sector, 19 % men and 15% women faced challenges to monitor their health status for giving priorities to income generating activities.

Qualitative data shows that men drivers who frequently travel out of Addis Ababa face difficulties in matching their drug refill schedules with their working condition. It is because drug refill is only possible at a place where treatment follow up is started. As a result, they either miss appointments or should go earlier and explain their case to take drug refill. An interviewee said:

I am a driver of heavy load truck. I frequently travel out of Addis Ababa and during some months I finish all my drugs before returning to Addis. I remember once I missed two days treatment despite my knowledge of dangers. I can not do anything except praying not get sick. I have a plan to change my job but until then I am worried about what I am going to feed my family. (B, Age 35)

From his words it is possible see that beyond the difficulties faced to monitor health status; men are also in stress to fulfill their expected gender roles that is to earn income to their families. This stress can force them to stay in a situation where their adherence condition is inhibited. The following table in general shows respondents' challenges of monitoring their health status.

**Table 10. Respondents experience of challenges of monitoring health status**

Item	Men		Women	
	Yes %	No%	Yes %	No%
Lack of transportation money	48	52	55	45
Household and caring responsibilities	-	-	37.5	62.5
Lack of permission from formal work places	17	83	11	89
Giving priorities to income generating activities	19	91	15	85
Travel out of the treatment site because of working condition/ family visit etc	24	76	17	83

Other	6	-	3	-
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Although health seeking behavior is a complex issue, studies showed that the health seeking behavior of men and women can be influenced by their gendered values and attitudes. The socialization process that teaches and expects men to be strong, endure pain, less complaint, indifferent etc. about their health may force them to seek treatment late even in the context of ART. Accordingly, findings of this study shows that aside from keeping drug refill schedules, men on ART can be late to report side effects, toxicities and other related sickness. This is confirmed by both the adherence counselor and ART nurse like the following;

Most men come to us after they develop serious side effects and toxicities, sometimes it even become difficult to treat them but it would have been great if they come early and decrease their risks of complication. Most of them believe that they are strong enough to overcome the pain. While most women come early when ever they see changes in their health status, they come even for a simple flu...

Male focus group discussants also mentioned that how their masculine values and attitudes including the need to hide their status sometimes tempt them not to seek health care services on time. A male discussant said:

Being a man, I am not expected to complain about simple headaches and run to clinics every time “like my wife” do. Rather I prefer to wait and see changes and at last if I am defeated, I go. (X, Age 45).

Such cultural values and attitudes indeed hinder men from monitoring their health status to the level ART use requires. Thus, it would unlikely for them to identify the long term side effects of ART and take action at the right time. In all the above discussions, it is generally noted that contrary to what feminists presume, men on ART can also suffer challenges from the existing gender based norms and values.

#### **4.4.4 Khat and Alcohol use**

Both qualitative and quantitative data shows that the use of Khat<sup>5</sup> and alcohols are at the minimal levels among ART users in this study. However, this does not mean that there are no individuals who take alcohol while they are living with ART. Interview and focus group participants gave their testimonials about some very young and older men they know who take Khat and alcohol with ART. A female discussant said:

In my village, I know two old men who are living with ART and go to local drinking places every night. I know the owner of that place and she told me that she saw them taking the drugs when ever they remember. They often visit sex workers also but day after day their physical condition is deteriorating. (F, Age 32)

A female interviewee also said:

I have a friend who lives with ART, her husband drinks alcohol, chew Khat and take ART. She is always worried about him as he does not take his medications properly, lost his appetite and sense of self worth. She is also in trouble as he sometimes forces her to sleep with him which is more dangerous for both of them. (Y, Age 34)

From such testimonials, it is possible to state that men who use alcohol and ART together are putting not only their own health in danger but also their partners. Previous studies also confirmed that the high association among alcohol use, unsafe sexual encounters and violence against women. This implies that, though women themselves do not use alcohol they could be equally exposed to the dangerous consequence of alcohol and ART use.

On the other hand, for some of male participants, discovering their HIV positive status and starting ART has rather become the limbo of their life with alcohol and Khat. Some male focus group discussants were able to compare their life before and after ART. A male discussant said:

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<sup>5</sup> Green leaves of a plant that grew mainly in eastern parts of Africa and Yemen when people chewed the leaves acts as a stimulant

I used to chew Khat, drink alcohol a lot and I go out with different girls while my wife was at home. I know this behavior of mine resulted in my HIV infection as well as my wife. When I knew my positive status after repeated illness, I began decreasing such addictions and when I finally started ART I stopped everything. Now, I feel pity for what I had been through. My wife has not yet started ART. Now I take care of her since she decided to stay with me despite what I did to her. (X, Age 45)

At this juncture, it is important to note that because of the transformed behavior of men, not only men themselves benefit but also women whose life in one way or another is related to men. The survey result also confirmed that 21.7% men quit their alcohol and Khat use after they discovered their HIV status and later started ART. Moreover, only 2% men said they use alcohol and Khat currently while none of women respondents reported the case.

However, qualitative data shows some men and women participants infrequently drink Tella<sup>6</sup> with the belief that this drink has reduced amount of alcohol than other types. Particularly older men because of the social and cultural values associated with it they are growingly considering as normal to take Tella and ART. Contrary to this consideration, literature indicates that any type of alcohol has the potential to interact with ART and produce toxicities that endanger the health of the user.

#### **4.4.5 Safer Sexual Practices**

In the context of living with HIV and its treatment drugs, safer sexual practice is important. It is because unsafe sexual practices would likely to result in re-infection, STDs, unintended pregnancy and exposure to drug resistant HIV strains that can lead to the over all disease progression resulting in death. For this reason, abstinence and consistent and correct use of condom is the only available option to men and women on ART.

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<sup>6</sup> Locally prepared alcoholic drink brewed from different types of grains and yeast

As the health and wellbeing of men and women improves with antiretroviral therapy, they may reconsider previous decisions regarding their sexuality and reproduction (WHO, 2006). This is found out to be true as most of the participants in this study revealed that after they started taking ART and become healthy, their sexual urges and desire to experience parenthood revived which in former times disappeared because of repeated illness and despair. A male interviewee said:

Since the day I have known my HIV positive status, I developed hatred towards sex and women in general. For this reason, I abstained from sexual relations for many years. And when I am about to start ART, the adherence counselor was telling me the requirements of ART and when he was about to tell me that I should use condoms, I interrupted him and told him that I have already closed that chapter of my life. But when I recovered later, a new chapter is opened and this is not peculiar for me, I know some of my friends who have the same experience also. (Z, Age 42)

A woman interviewee also said:

I discovered my HIV positive status three years ago. I despaired about everything in my life and I never thought I will have sexual desire again. I abstained from any relationships and in the mean time I was experiencing different types of diseases. Finally, I started ART, a new life, a new binging, now I am healthy, full of hope and if I get someone who has the same status with me I am ready to marry and give birth. (T, Age 35)

Such resurrection however took place in circumstances where norms of sexuality are still dominated by men, where the decision of condom use is exclusively made by men and even more women are continually subjected to the experience of coerced sex.

Findings have shown that negotiating safe sex is not always easy for women than men. Particularly, married women on ART are not commonly in a position to negotiate consistent condom use despite their knowledge of risks and dangers. A woman illustrated her condition as follows:

I and my husband are living with ART. My husband is the only breadwinner to our family. We have 2 children who are free from the virus. My husband began taking ART 2 years ago and I am now on my 10<sup>th</sup> month. For the reasons of repeated illness, we stopped sexual intercourse long time ago. But now, I am caught in difficulties, despite my knowledge of consequences of unsafe sex he began forcing me to sleep with him. Every time I insist on condom use but sometimes we use other times we do not use. How can I refuse sex without condom? I have no where to go or income of my own, besides who will take care of my children if I left this marriage. (S, Age 29)

Her words reflect that the combined forces of unequal sexual power, lack of independent sources of income and child raising responsibilities forced women to stay in a relationship that exposes them to dangers of unsafe sex. Most female discussants also agreed that it is because of economic dependence that most women are unable to refuse unsafe sexual demands from men. Some others further asserted that fear of violence that follows a refusal of sex also have a role to play in forcing women to submit to their husbands' request. The survey result shows that 57% men and 33% women have sexual partners currently. This means that, in all these relationships the likelihood of women to refuse unsafe sex is there.

Apart from re-infection, in each unprotected sex, there is risk of unwanted pregnancy that has the potential to complicate the health of women on ART. Furthermore, presence of pregnancy means additional challenges for the woman; complicated health risks, responsibility of following PMTCT service, economic burden for alternative infant feeding and most of the child raising responsibilities will be shouldered by her than a man who forced her to unsafe sex.

Even when pregnancy is a desired one, women conceive to fulfill their cultural obligation, to counter social pressures and escape the stigma of being blamed infertile. A participant explained her reason of giving birth despite her knowledge of complicated risks as follows:

I have been living with ART for 3 years. My husband also takes ART. Our families and neighbors are suspicious of our status but because of ART we both are very healthy. I know the risks of unsafe sex and pregnancy to my health, but I decided to give birth to show people that I am fertile, capable of being a mother. Particularly, to my mother-in-law who always gossip about my being late to give birth. I followed up PMTCT service closely and gave birth to a healthy daughter now she is 11 month old.( W, Age 24)

Her experience tells that even if men do not actually force women to unsafe sex, the socio cultural expectations and pressures on women can force them to take risks. And such pressures have been witnessed to force women to the extent of making decisions to sacrifice their life.

Female discussants further informed that the other problem women are facing in negotiating safe sex is that some men dislike condoms and men are usually influenced by myths associated with it. Such widespread myths mentioned by discussants include condoms decrease natural pleasure, men who usually use condoms develop allergic, condoms themselves can bring AIDS etc. As a result, even though men know risks they become reluctant to use condoms regularly which in return dangerous for themselves as well as to their partners. (An attempt was made to explore condom related issues among the male participants in this study but all interviewees and focus group participants told that they regularly use condoms and not influenced by myths, they generally become reluctant to discuss the issue.)

The fact that barrier methods are only developed for men so far reduced women's ability of protecting themselves from unsafe sexual encounters. In this regard, women interviewees and discussants repeatedly disclosed that in what ever cases they want to protect themselves but the unavailability female control methods limited the realization of their desires. Some participants of course heard about female condoms but never got a chance to use it.

Qualitative data shows that men in all the aforementioned contexts are in a better position to decide about their sexuality, to use or not use condom and to force or not a woman to unprotected sex. Nevertheless, women's relative powerlessness to decide about their sexuality left them to the risks of re-infection and contracting drug resistant HIV strains. Here, the feminist concern is found out to be true as compared to men women's ability to practice safe sex in the context of ART use is very limited.

#### **4.4.6 Opportunities**

Despite of all challenges men and women on ART are confronting with, they are able to identify aspects of opportunities that can improve their life with their medications. However, as compared to the diversity of challenges, opportunities are found out to be limited.

Almost all men and women participants witnessed that because of ART their health is in a very good condition, their sprit of work, education and self advancement has elevated to higher levels. They also mentioned that ART builds physical strength, enables one to compete with any life challenges as equally as other non infected people. Above all, many of them stated that ART has fulfilled their desire to live more despite having HIV positive status.

The fact that provision of ART is free from any payment is found out to be one of the significant opportunities for many participants in this study. A female participant said:

It is because ART is free I became equal to every one now. Otherwise, I would have remained bed ridden of course died by now. I would like to express my heartfelt thanks to our government who provided us this life prolonging opportunity. (K, Age 36)

A male participant also said:

I remember those days when people were buying ARVs with high price. During that time, I used to pray a lot not to reach to stage of ART. But now ART is free, I am very lucky to be part of this generation; because I know some of my friends who passed away lack of access to ART. (H, Age 33)

Survey results also confirmed that the majority 98.2 % of men and 97% of women mentioned free provision of ART as one big opportunity. (See table 11).

Moreover, as predicted by WHO and other international organizations, the provision of free ART service is ensuring gender equality in access to treatment. The recipient profile of Zewditu hospital indicates that there is equal number of men and women ART users. In addition, the national figure shows that the number of female ART users is slightly greater than that of men. Therefore, provision of free ART is particularly benefiting poor women who would be left out if ART was on fee basis.

Furthermore, findings have shown that some of the participants mainly women with children are able to receive food assistance from different NGOs. Though many explained it is not enough and on the verge of discontinuation, the assistance is helping women to cope up with food shortage in the household and it has brought positive impact upon their adherence to their medication. As a female discussant said:

I receive 25 killo wheat and 4 liters oil every month from World Food Program. This means a lot to me and my family; with out this food assistance life would be difficult. But having a large family it is not enough and in fact the amount is decreasing time after time. (N, Age 28)

On the other hand male participants in mixed sex focus group discussion expressed their disappointments about their exclusion from the provision of food assistance. Particularly those men whose wives passed away and have the responsibilities of raising children reported that they are facing difficulties. A male discussant said:

Many NGOs consider men as rich, doing well in life but the fact is different living with HIV and experiencing repeated illness by itself takes away all your energy many of us quit our jobs, lost our source of income and even after ART getting employment opportunities is difficult. We are also suffering... We are discriminated because of the general assumptions made about men.( SL, Age 37)

His words indicates that gender based assumptions does not always hold true. But rather some men are also discriminated because of the generalizations made about their situation. The survey also shows that 14% women and 4% men receive food assistance from NGOs.

Participants who disclosed their status to their families and have been receiving various types of support mentioned that, family acceptance as the most important opportunity in their life with ART. Previous studies showed that family acceptance and support plays essential role in promoting treatment adherence and creating psychosocial comfort that would ease the burden of taking ART. A female interviewee said:

I am living with my older sister family, her husband and children know my status and provide me all kinds of support. They remember my pill taking time; give me food on time, love me and many other things... it is because of them my life is partly extending. (T, Age 35)

A male discussant also said:

I and my wife are living with ART, we support each other, our children also knows our status they encourage us a lot and I even sometimes forget that I am living with HIV because of them. (X, Age 45)

In the survey, 62.3% men and 57% women respondents identified family acceptance as the most important opportunity in their life with ART. Although it is difficult to state that all of them share similar types of

Some male participants who have formal employment disclosed that they are receiving financial assistance upon disclosure of their status to at least one management personnel. This financial support is helping them to fulfill the requirements of ART. A male interviewee said:

I am a private company employee. In addition to my salary, I receive 600 birr which is a lot for me to supplement my dietary needs. Every month, I have also one day permission to go to hospital for health check up and drug refill. (G, Age 38)

Such opportunities definitely can be accessed more by educated men who have formal employment and women still remain in the periphery to benefit from these types of opportunities opened for persons taking ART. The following table shows participants responses to identified opportunities.

**Table 11. Respondents' experience for types of opportunities identified**

Identified Opportunities	Male		Female	
	Yes%	No %	Yes%	No %
Free provision of ART	98	2	97	3
Access to food assistance	4	96	17	83
Access to financial assistance	11	89	6	94
Family acceptance and support for adherence	62	38	57	43
Other	2	-	2	-

Recently the Ministry of health disclosed that the process is already finalized to replace triple therapy by mono therapy. It means that patients will take only one pill per day rather than 3 or 4 pills like in the previous times. By this, the burden of adherence is expected to be lessened. The adherence counselor is optimist about the replacement that could benefit all but uniquely poor older women as they sometimes confuse and skip doses for different reasons.

## **5. SUMMARY AND CONCLUSION**

### **5.1 Summary**

This study has attempted to reveal challenges and opportunities that men and women encounter in their day to day effort to fulfill the requirements associated with ART. It has employed gender based approach in order to identify the condition of women vis-à-vis men. The requirements under which men and women were examined include adherence, monitoring health status, nutrition, drug and alcohol use and safer sexual practices. In all these requisites lies the issue of gender.

With regard to adherence which is a complex issue and that constitute aspects of missing doses, not keeping time intervals and respecting food and fluid restrictions, it is found out that poverty, gender based violence and fear of stigma are the basic problems influencing adherence.

Although both men and women face the challenges of poverty, women's lack of independent income, housing and their subordinate status to men makes it hard for them to properly adhere to their treatments. Furthermore, because of their gender women are distinctively vulnerable to the experience violence, findings showed that in the new era of the HIV epidemic this violence is taking a new form and women are subjected to irregular adherence and drug interruptions because of the cruel acts of their male partners and employers.

Fear of stigma is the other factor influencing adherence. Since many people still have negative perceptions of HIV, persons on ART fear loss of employment, loss of income, rejection by family/partner , expulsion from home etc. if they disclosed their HIV positive status and if seen taking ART. Therefore, many of them prefer to pass time or skip doses in order to avoid status disclosure. Here, the low socio cultural and economic status of women means that women fear the negative consequence of stigma in much broader ways than men.

Men and women on ART are expected to go to health centers at least once in a month for drug refill and for monitoring CD4 and viral load status. To do so, it requires costs related to transportation and time. Women are more challenged by

lack of transportation money and because of their household responsibilities it becomes difficult to respect appointment dates and drug refill schedules. Men in this instance are challenged by lack of permission from their work place, the nature of their working condition that require traveling out of the treatment sites and the gendered beliefs and attitudes they held about their own health.

Good nutrition is one important aspect of living with ART. However, findings revealed that poverty in general limits men's and women's access to adequate amount of food. Further than this, food related gender norms determine taking even what is available at the household. Many men participants informed that because of their gender roles they find it difficult to prepare and serve their own food, this indeed has impact on keeping specific drug taking frequencies. For those poor men on ART, such challenges made them to decide to prepare their own food demonstrating the possibilities of shift in gender roles. While findings showed that there are women who prefer giving food priorities to family members, making themselves to eat small amount left or not.

The study has shown that the use of Khat and alcohol is minimal among men and women ART users. For some men, the discovery of their HIV status and starting ART has become a cut off point from their addiction to alcohol and Khat. By this, some men reported that they reduced their risky and violent behaviors towards women. This in turn generated safety and relief for women whose life in one way or another found related to men.

Because of ART the health and wellbeing of men and women living with HIV has improved a lot. They have witnessed a lot of changes in their life among which is the resurrection in their sexual desire and need to have children. However, such resurrection took place in a condition where sexual power is controlled by men and where women have limited negotiation power over the use of condoms. Findings showed that despite their knowledge of risks women particularly married women are still vulnerable to re-infection, drug resistant HIV strains and unwanted

pregnancy because of the refusal/ reluctance of their husbands' to use condoms on regular basis.

Despite all challenges men and women encounter to fulfill requirements of ART there are aspects of opportunities identified. These include the very fact that ART is free of payment, food assistance targeting poor women and children, men in some organizations are receiving financial assistance upon disclosing their status to the personnel management. The on going effort by Ministry of health to replace triple therapy with mono therapy is going to be one big opportunity as patients will take only one pill per day instead of three and four with strict time and food schedules. This will particularly benefit poor, older and uneducated women who are unable to properly follow drug regimens.

## **5.2 Conclusion**

The increasing availability of free antiretroviral therapy in Ethiopia has indeed given a new hope to men and women living with HIV. Nevertheless, it has also presented new challenges to fulfill the user side requirements associated with it. These challenges have similar and different faces for men and women because of the underlying socio-cultural and economic differences that framed their lives. Since participants of this study were drawn from different walks of life and from different socio- economic status, it makes it difficult to draw a clear cut conclusion and generalization about the gender dimensions of challenges and opportunities encountered.

However, this specific study has shown that gender based differences in social, cultural and economic contexts could play a role in challenging men's and women's ability of meeting the requirements of ART. In this regard, women's subordinate status, weak economic stand, vulnerability to violence, devalued social status and their inability to negotiate safe sex have relatively made their challenges worse than men. But this does not mean that men are at the comfort zone to meet the requirements of ART, rather men in some situations are also at a disadvantage because of rigidly defined gender norms and the multifaceted nature of poverty. Regarding the limited opportunities identified as compared to the diversity of challenges, the gender dynamics have also been witnessed to influence one's ability to have access to existing opportunities.

At last, since this study did not exhaustively go through all the challenges and opportunities ART users face, a further exploratory study is important to reveal the remaining aspects of ART use and how men and women are generally coping with the difficulties of meeting the requirements of ART.

## **6. Recommendation**

Based on the findings of this study the following recommendations are forwarded to the concerned bodies that include MOH/HAPCO, Ministry of women, Ministry of justice, local and international NGOs working on Gender and HIV and local associations providing help to HIV positive people.

- Beyond increasing the roll out for free ART, sufficient attention should be given to challenges users face in meeting the requirements associated with ART. In this regard, gender based differences should be duly acknowledged and addressed.

- Provision adequate treatment literacy should go parallel with the increasing number of persons taking ART. Treatment information should also be given to the general public through different means.
- Adherence counseling and treatment follow up should be strengthened and counselors should be trained on gender issues so that they could understand the social position of women and its implication to adherence.
- Treatment provision sites should create a mechanism to consider the convenient hours and living conditions of men and women users.
- ART programs need to be sensitive to women specific needs, especially in relation to their sexual and reproductive health. Additional counseling and reinforcement of adherence for women is important during pregnancy and child birth.
- Laws should be amended and enacted that respond to the newly emerging ART related gender based violence.
- Economic empowerment of ART users must receive sufficient attention by both government and non governmental organizations. Income generating means should be created particularly to poor women who have burnt the interwoven social and economic crisis of HIV/AIDS.
- Social support programs should be strengthened/ devised in order to decrease stigma towards PLHIV in general and in particular to those poor women who are living with ART.
- Nutritional support in relation to provision of ART should be provided to poor men and women. This support must focus either on sustainability or enabling them to generate their own income that can ensure their food security.

- The already strengthened prevention activities must continue and include components of providing basic ART related information to the general public.
- Promoting female controlled barrier methods like female condoms and microbicide is important in protecting women on ART from risks of re-infection, unwanted pregnancy and any other reproductive health problems.
- In general, increased awareness on gender issues and their reflections in every aspect of life is important to address the specific needs of men and women living with ART.

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