

Running Head: Assessment on Needs of ART Consumers

**ADDIS ABABA UNIVERSITY
SCHOOL OF GRADUATE STUDIES
GRADUATE SCHOOL OF SOCIAL WORK**

**Assessment on needs of ART Consumers in Addis Ababa: The Case of 20 ART
Consumers at Alert Hospital**

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(MSW)**

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Acronyms

AAHB-	Addis Ababa Health Bureau
AAHPCO-	Addis Ababa City Government HIV/AIDS Prevention and Control Office
AIDS-	Acquired Immunodeficiency Syndrome
ARV-	Antiretroviral Drugs
ART-	Antiretroviral Therapy
CBO-	Community Based Organization
CCoCM-	Comprehensive Continuum of Care Model
CD4 -	Cluster differentiated 4 T lymphocyte cells
CSA-	Central Statistical Authority
ECA-	Economic Commission for Africa
FDRE-	Federal Democratic Republic of Ethiopia
GO-	Governmental Organization
HAART-	Highly Active Antiretroviral Therapy
HBM-	Health Belief Model
HAPCO-	HIV/AIDS Prevention and Control Office
HIV-	Human Immunodeficiency Virus
ICRW-	International Center for Research on Women
IEC-	Information, Education and Communication
INGO-	International Non-Governmental Organization
MOH -	Ministry of Health
MSC-	Medhin Social Center
NGO-	Non-Governmental Organization
NPOEW-	National Policy on Ethiopian Women

PIH:	Partners in Health
PLWHA-	People Living With HIV/AIDS
TB-	Tuberculosis
UN-	United Nations
UNAIDS-	Joint United Nations Program on AIDS
WHO-	World Health Organization

Abstract

A qualitative explanatory research was deployed to assess the needs of ART consumers in Alert hospital who are residing in Kolfe Keranio sub city Kebele 02/03. The study participants are People Living with HIV/AIDS (PLWHA) who are selected purposely based on years of experience taking ART, their communication skills. The primary data was collected through in-depth interview and observation guide. In addition, secondary data sources were used to obtain information on total number of ART consumers at Alert hospital and national level. The study shows that need for nutritious food, employment, financial support, human right, own or Kebele accessed houses as major needs of participants of this study. Furthermore, the study revealed that many of the participants are in a weak economic condition, which is found to adversely affect them from meeting their needs which results for weak adherence. The study has also revealed that males needs access for job and female family members who can provide them support while females are found to have a different need for safety within the home environment and access for prior service at health posts. Finally, the study has identified a social work practice that aims at training ART consumers on income generating activities based on their prioritized needs, skills, interest and capacity besides complementing the program by providing education on stigma and discrimination to the public so that they will contribute their share in supporting the effectiveness of the program.

Chapter one

Introduction

Acquired Immuno Deficiency Syndrome (AIDS) has infected and killed millions of people worldwide. According to the United Nation Program on AIDS (UNAIDS) (2004), AIDS has claimed the lives of more than 25 million people since it was first recognized in 1981. The number of people living with HIV/AIDS (PLWHA) reached an estimated 40.3 million, and close to 5 million people are newly infected with the virus in 2005. AIDS has killed 3.1 million people in the same year. Two thirds of all people living with HIV/AIDS reside in Sub-Saharan Africa (UNAIDS & World health organization (WHO), 2005).

Ethiopia, with a current estimated population of above 73 million (Central Statistics Authority (CSA), (2004) is the second most populous country in Sub Saharan Africa. It is also known as one of the poorest nations in the region encountered with challenges from different sectors. Those sectors include economics, political areas, social welfare, education and health among others (Ministry of Health, 2006).

In Ethiopia, AIDS patients occupy more than 50% of Hospitals' beds. This has brought great pressure on quality and quantity of the provision of care and support provided to PLWHA that overwhelm the public, private and non-governmental organization (NGO) responses to the epidemic (HIV/AIDS Prevention and Control Office, 2006). AIDS has impoverished individuals since many of the infected people expend their resources and time in search of treatment which as a result push them seek care and support from Governmental Organizations (GO), NGO and Community Based Organizations (CBO). It is also adversely affecting the effort made by different institutions and organizations by reducing the productivity of individuals (HAPCO, 2006).

The epidemic is also affecting young people disproportionately. Infected people between 15-24 years old account for half of all new HIV infection worldwide and more than 6,000 contract the virus every day (UNAIDS, 2004). Sharing this point, Blair and Hein state that seven million people who are infected with HIV were within the ages of 15 and 24. These scholars have also asserted the higher devastating effects of HIV/AIDS on adolescents as compared to other age groups and communities. The situation in Ethiopia is not far from this fact (HAPCO, 2006) since 34% of all young adult (15-49 years of age) deaths and 66.3% of these populations in rural and urban Ethiopia is attributed to AIDS (MOH, 2006).

The uncontrolled expansion of HIV/AIDS had become a threat to millions of people all around the globe in terms of its adverse impact on health, economy and social services. This epidemic is seriously affecting regions of the Sub-Saharan countries more than any other nations. As a result, countries in the region have lagged behind their development activities and effective provision of care and support for their citizens infected with and affected by the virus (UNAIDS, 2004).

Several nations have recognized the impact of HIV/AIDS on health, economics and political system that deterred them from providing effective care and support to PLWHA. In response, they have put in to place relevant policies and guidelines, which emphasize not only on method of prevention and control of the epidemic but also the ways to provide safe and effective care as well as support to PLWHA including Antiretroviral therapy (ART).

Guideline, which is produced by the WHO on safe and effective provision of ART for resource-limited countries, is a document that is adopted by many developing countries including Ethiopia (WHO, 2006). The guideline states the decision for initiation of ART to AIDS patients in developing countries is based on clinical and immunological assessment. Accordingly, WHO recommends initiation of ART when CD4 count is greater than 200 but

less than 350. It also recommends that lack of Cluster differentiated 4 T lymphocyte cells (CD4) count should not delay initiation of ART if the patient is clinically eligible (WHO, 2006).

Similarly, in recognition to the vast damage inflicted because of AIDS and competing demands of equal magnitude of the problem with malaria, famine, and Tuberculosis (TB), MOH has prepared a guideline for an effective and safe use and implementation of Antiretroviral Drugs (ARV) in January 2005. This guideline aims at supporting the development of standardized, safe and effective ART program. Consequently, the government of Ethiopia has started to introduce ART program with the goal to prolong the lives, restore the mental and physical condition and to improve the quality of life of PLWHA (MOH, 2006; MOH, 2005).

A total of 265,358 PLWHA were estimated to benefit from the ART program in Ethiopia. However, at the national level, only 35,460 PLWHA were on ART until June 2006. In Addis Ababa, there were about 241,000 and 246,000 PLWHA in the years 2003 and 2004, respectively. These figures are projected to rise to 264,433 and 271,440 cases in the respective years of 2007 and 2008. According to Addis Ababa Health Bureau (AAHB) (2006), the adult HIV/AIDS prevalence rate in the capital is 14.6%. This report has also estimated that 47,156 people in Addis Ababa are in need of ART until May 2006. Furthermore, Addis Ababa has registered nearly half of the total number of patients on ART in ten hospitals (AAHB, 2006). Alert hospital has started to launch free ART program since January 2005 with the help of international non-governmental organization (INGO) and continued its provision of service by receiving free ARV since June 2005 from the federal ministry of health (AAHB, 2006).

Problem Statement

Globally, estimated five to six million PLWHA are in need of ART. However, those who have access to ART service are not more than 7% in the low and middle-income countries (UNAIDS, 2004). According to a joint report of UNAIDS and World Health Organization (WHO) (2006), some sub Saharan countries like Botswana, Uganda and South Africa have accessed 85%, 51% and 21% for ART service respectively. Even though some countries are in positive progress in accessing the service to the needy, as ministry of health (MOH) reported, countries like Ethiopia have accessed the service only for 7 % of PLWHA who need the service (2005). Besides the limited coverage of ART service in Ethiopia, according to MOH (2005), challenges for accessing and scaling up ART service is observed due to the poor capacity of health centers and limitations in number of health professionals as well as the imbalance between need for the therapy by PLWHA and the existing economic conditions of the country.

According to the MOH, (2005), around 245,000 PLWHA were in need of ART in the year 2003. However, in its sixth report on AIDS in Ethiopia, MOH indicated that the number has grown to 277, 800 in the year 2005.

Currently, ART is provided free of charge to PLWHA who are in need of it with the purpose of improving their quality of health (MOH, 2006). The 2000 report of UNAIDS commented that, ART is complex in its nature because its administration is linked with nutritious food, stress free environment and positive/healthy living conditions. However, the existing ART service is launched to PLWHA without undertaking in-depth and adequate need assessments related to ART consumers' social, physical and material need.

More specifically, there is also lack of assessment made in understanding gender-based variation in relation to the needs of PLWHA. Furthermore, the needs that lead ART consumers for weak adherence were not properly investigated.

Though studies conducted, on the needs of ART consumers can have an important impact on the improvement of effectiveness and safe provision of the therapy, it is one of the areas, which is left untapped in research. Safe and effective provision of ART requires a special focus in provision of clinical and non-clinical care to bring about the expected result on people that are taking the therapy. Hence, studies conducted with the aim of assessing the needs of ART consumers in relation to comprehensive responses provided to PLWHA from different domains of care will contribute in indicating the shortcomings of models of care that are used to provide care and support to ART consumers. Furthermore, in order to accelerate the provision of ART through out the country, to make the service easily accessible to most of the consumers, and to effectively provide the service to those who have already started the therapy; assessment of needs related to ART consumers' material, social, environmental, and emotional needs seek special consideration. Therefore, cognizant of the importance of undertaking need assessment on ART consumers, this study targets to assess needs of ART consumers at Alert hospital.

Therefore, conducting research targeted at assessing and understanding the major needs of AIDS patients who are consuming ART will have invaluable contribution in indicating priority-seeking areas for social work intervention besides adding some knowledge to the discipline and indicating alternative ways for addressing the needs of ART consumers.

Scope of the Study

The scope of this research is limited to ART consumers in Addis Ababa at Alert hospital with particular emphasis to those who reside in Kebele 02/03 of Kolefe Keranio sub city. The total numbers of PLWHA who are taking ART in Alert Hospital are 3,583(AAHB, 2006). The study has made its focus on ART consumers, who have at least

made a month since they started receiving ART. This is purposely done with the purpose of assessing earlier and later challenges and needs that faced ART consumers.

This study is also limited in scope to assessing material, economic and social needs of ART consumers and the existing relations between economic status of ART consumers and causes for their weak adherence to the therapy. The study did not cover medical needs, challenges related to client- service provider relations.

Objectives of the Study

General Objective

The overall objective of this study is to assess major needs of ART consumers who reside in Kolfe keranio sub city Kebele 02/03 and receive ART service from Alert hospital.

Specific Objectives

The study has the following interconnected specific objectives

1. To describe the major needs of 20 ART consumers who receive ART service in relation to the enabling environments.
2. To find out how the economic condition of ART consumers relate to their major needs.
3. To assess gender based need differences among ART consumers.
4. To assess needs that relates to the cause for weak adherences.

Operational Definitions

ART: is the administration of at least three different medications d4t+azt (proven antagonism), d4t+ddI (overlapping toxicities) and 3TC+FTC known as ARV drugs in order to suppress the replication of HIV and stop the progression of HIV disease. (WHO, 2006)

Adherence: The patient's ability to follow a treatment plan, take medications at prescribed times and frequencies, and follow restrictions regarding food and other medications (horizons/population council, 2004).

Assessment: The deep exploration of material, social, and emotional needs of ART consumers through collection, organization, and analysis of information.

Therapy: a treatment designed to improve the health status (both physical and psychological) of AIDS patients (WHO, 2006). In this study, treatment and therapy are used interchangeably.

Opportunistic Infections (OIs): are disease sign and symptoms indicating AIDS progression (WHO, 2006)

Side Effects- the unintended adverse outcome and expected disadvantages of ARV drugs and treatments on ART consumers.

Need: the physical and social gaps that ART consumers feel and experience in the process of taking ART as a life long therapy.

Positive Living with AIDS: maintaining a positive attitude towards oneself and others. not blaming others, not feeling guilty or ashamed, following medical advice continuing to work if possible, occupying one with non-stressful activities, socializing with friends and family, using condoms during sex, and avoiding pregnancy (UNAID, 2004;WHO 2006)

Weak Adherence: the inability to take prescribed tablets and medicine at prescribed times and frequencies and failure to stick to restriction in food and other medication (WHO, 2006) and the inability to take the tablets with recommended food.

Chapter Two

Literature Review

This chapter presents a summary of literature with the intent of providing existing literature that contributes towards assessing the major needs of ART consumers. To this end, two models namely: the Health Belief Model (HBM) and the Comprehensive Continuum of Care Models (CCoCM) were discussed and the later was used as a base for constructing a conceptual framework together with literature on empirical research. On top of this, presentations on local trends of provision of care and support to ART consumers were made.

AIDS in Ethiopian context

Ethiopia is one of the nations that are seriously challenged with HIV/AIDS among the countries in Sub Saharan Africa (UNAIDS, 2006; MOH, 2006). According to MOH (2006), HIV/AIDS prevalence in Ethiopia in the year 2005 was 3.5%. Out of this, the urban prevalence rate took 10.5% while it is 1.9% in rural areas of the country. The same report depicts that, of the total estimated 73 million people in the country, there were an estimated 1,320,000 people living with the virus in the year 2005. Out of these PLWHA, 634,000 and 686,000 are living in rural and urban areas respectively.

There were an estimated 137,500 new AIDS cases and 128,900 new HIV infections (353 per day) in the year 2005. In addition, there were more women living with the virus than men between 15-29 age ranges. However, there were more men compared to women living with the virus in the age group of 30+ years. It was also estimated that there were a total of 744,100 maternal, paternal and dual AIDS orphans in 2005. HIV/AIDS has

accounted for 32% of the estimated 141,000 of Tuberculosis (TB) cases in 2005 (MOH, 2006).

Addis Ababa, the capital of Ethiopia, hosts an estimated population of 3,164,411 (AAHB, 2006). In this city, there were about 241,000 and 246,000 PLWHA in 2003 and 2004 respectively. These figures are projected to rise to 264,433 and 271,440 cases in the respective years of 2007 and 2008. The adult HIV/AIDS prevalence rate in the capital is 14.6% (AAHB, 2006; MOH, 2004).

One of the good achievements in the fight against HIV/AIDS is accessing antiretroviral (ARV) drug. According to WHO, (2006), 1.6 million people across the world have accessed ARV drugs even though other 6.8 million people has been waiting for the service (WHO, 2006). In similar development, Ethiopia has started launching free access to ART programs at different health posts across the country since January 2005 (MOH, 2006). However, only 7% of the total people who seek the service have accessed ART until the end of July 2006. This program is also intended to benefit 265,358 PLWHA. Surprisingly, 50% of people receiving ART are from Addis Ababa (MOH, 2004; HAPCO, 2006)

Major Responses Endorsed to Mitigate the Spread of AIDS

To avert the alarming growth of the epidemic in Ethiopia, the government has put two major policy documents namely: 'HIV/AIDS policy' with the objective of prevention and control of the epidemic, and the Ethiopian 'Multi sectoral strategic frame work', with the aim of coordinating the efforts of different sectors in 1998 and in 2002 on place respectively. A national taskforce and national HAPCO were established under the control of the prime minister with chief purpose of mobilizing resources and coordinate sectoral responses. Furthermore, guideline on the implementation of safe and effective provision of ART in Ethiopia is prepared by the ministry of health in 2005 with primary goal to support the development of a standardized, safe and effective ART program nation wide (MOH,

2006). In similar way, Addis Ababa health bureau has prepared a road map aimed at planning the implementation and scaling ART program to reduce AIDS related morbidity and mortality and increase the quality of life of AIDS patients (AAHB, 2006).

Recognizing the impact of ART in enhancing the quality of life of AIDS patients in terms of lessening morbidity, mortality and number of deaths, the government has started to launch free ART service since January 2005. However, only 7% of those who seek for the service have accessed it (MOH, 2006). The UNAIDS report also depicts that out of the global five to six million people who seek ART in 2003, only 7% of them who are in low and middle income countries have accessed the treatment (UNAIDS, 2004).

According to MOH (2006), there were 277,000 people who require ART in 2005. Among these, 43,100 were children. By the end of July 2006, a total of 45,595 patients had ever started on ART at 132 facilities across the country.

Importance of ART and its General Impacts on AIDS Patients

To challenge the impacts of HIV/AIDS on human kind, a number of efforts have been made by different governments and organizations. Of these efforts, safe and effective provision of ART is a current alternative in the endeavor not only of reducing the number of deaths and number of orphan children but also of increasing quality of life of PLWHA. In addition, it improves the health status of many PLWHA found in different parts of the world.

ART has the power of reducing morbidity, mortality, and rates of transmissions of the virus as well as increasing the quality of life of AIDS patients if it is administered safely (Geoff p et al 2002; WHO/UNAIDS, 2005; and UNAIDS 2006). However, according to Youssef et al, (2002) achieving full adherence to ART is posing a fear to this opportunity.

Mckerrow, (2002) also argue that any type of treatment in general and ART in particular, by it self, is not effectual unless treatment receivers adhere to a medication. In his

study, Mckerrow, (2002) also indicated that men, compared to women, adhere more to medication because of the help they got from their female counter part. Nonetheless, women are found not being assisted and provided care by their male counter parts in the process of adherence for medication.

In addition, the availability and safe use of ART promotes community out reach which results in developing at ease environment for people to talk freely about HIV/AIDS ,which as a result, contributes in breaking down stigma and discrimination (UNAIDS 2006).

The study conducted by Jani, (2006) asserted that material support, especially of support related to food, community and family warmth positively contributes to adherence. The presence of family members, peers and fellow friends can encourage individuals' medication taking behaviors (WHO, 2006).Furthermore, HAPCO/ARC, (2004) asserted the importance of involving the community in reducing stigma and hence improve adherence among ART consumers.

Possible Positive Impacts of ART on AIDS Patients

According to WHO (2005), ART has a potential to reduce the viral load of HIV virus in the patient's blood. It also results in increasing the immunity of the patients by reducing the probability of recurrence of OIs and sexually transmitted diseases. This, according to MOH, (2006) will give opportunity to AIDS patients to impart their potential and to contribute their share in controlling spread of the epidemic. If ART consumers are provided with safe and effective therapy, they can impart their potential in productive works since absenteeism from work decreases and their physical status improves for the better. This also brings about improved involvement in productive works because of their improved health status.

Importance of Adherence to ART

ART has a lot of positive implication for an HIV positive patient in prolonging live, restoring the physical and mental functions and improving the quality of life of PLWHA. To attain these positive aspects of the therapy, a minimum of 95% adherence is required to be achieved by ART consumers, (WHO 2006). Therefore; adherence to treatment is a vital point for assuring the effectiveness of treatment and securing health goal of patient.

According to WHO (2006), ARV drugs are taken in combination and are termed as Highly Active Antiretroviral Therapy (HAART). HAART result in suppressing the virus to undetectable level but may result in pill burden, drug complications, and early drug resistance. A study conducted by Goldman and Smith, (2002) similarly capitalizes the importance of strict adherence to therapy, not of being simple follower of a therapy, which will absolutely lead to achieving a better health out come. One of the out come of a successful treatment is weight gain by patients, which in turn, has a direct reinforcement from adherence to therapy that can lead to bettered health and resistance of the human body.

Castro, A. (2005) argues in similar pattern about the importance of understanding the social, psychological and individual contexts of ART consumers for better adherence to the therapy. This argument asserts the idea that the better physical and psychological status and individual understanding ART consumers have, the greater they adhere to the therapy and the greater the result of the therapy will be.

Causes for weak adherence and possible negative impacts of ART

Castro, A. (2005) states that financial constraints, stigma and discrimination, travel, problems at work place, unemployment, and religion as factors that adversely affect adherence to ART among its consumers.

In spite of the aforementioned challenges to adherence, which reduce the advantages that one can obtain from ART, Mckrrow, (2002) note that compared to the different

methods that were applied for treating AIDS patients some time before ART, the method of ART for treating AIDS patients is much more effective. However, they recognize that this method of treatment is too complex because of frequency in intake and large number of pills to be taken by the patient. The therapy also demands patients to integrate nutritious meals and pills of the same or different types.

Contrary to the perspective to Mckrrow, (2002) on the combination of different regimen as a cause for non adherence, Schwartlander, et al.,(2001) stress that the presence of combination of regimens in a logical extension of current therapeutic approaches, rather not of threat, in the treatment of AIDS with a potential to reduce toxicity.

According to MOH (2006), weak-adherence to medication because of reasons related to treatment failure and presence of toxicity and side effects on the part of the patient may possibly result in either halting or ceasing the therapy for some days or for longer period. Halting treatment will lead to weak adherence, which as a result, can create an opportunity for the development of resistant retrovirus that in turn crumples the total endeavors of the therapy. It is also stated in this report that weak adherence for medication has relation with high stigma and discrimination which the society forward on AIDS patients.

General Needs of ART consumers

For people who receive a therapeutic care like ART, some of their basic needs require to be fulfilled because these needs can have relation with the effectiveness of the therapy. Partners in Health (PIH), 2004 states that socio economic status has a direct relation with success of treatment. It further depicts the importance of balanced nutrition that has to be taken by these kind of patients, not less than the therapy it self. It also asserts that shortage of nutrition and/or malnutrition perpetuates the viral duplication in the patient's blood, which in turn affects the health situation of patients. In addition, AIDS

patients need to have access for clean water that reduces the development of risk related to different common and opportunistic pathogens. Otherwise, it can facilitate their ill health by worsening the immune function thereby affecting the health situation of patients. Adequate, not over crowded and well ventilated house is also one of the needs of AIDS patients that have to be considered since there can be a potential spread of infectious pathogens like TB in unventilated and dilapidated houses including those that are situated in slum areas (PIH, 2004). Similarly, Shaikh and Hacher, (2004) asserted the impact of poor socio-economic status, cultural beliefs and perceptions, low literacy level and large family size as leading factors that causes poor utilization of primary health care services.

HAPCO (2006) ;WHO (2006) also recognize the important roles food and nutrition play in achieving, and preserving better health among patients by protecting the body from diseases. This, as a result will improve the quality of health of PLWHA and delay the progression of HIV/AIDS related diseases. It is also stated that stigma and discrimination are bringing a huge challenge in creating a stressful and discomforting environment for PLWHA, which in turn, adversely influence adherence to the therapy and effectiveness of the therapy.

Supporting this point, Annanaia, (2002) notes the impact of positive living among AIDS patients if they have access for more support from care providers, families, 'significant others' and society at large. For a continued care, forming partnership among health service providers, community based organizations (CBOs) and other stakeholders around the agenda can positively contribute in the attainment of the goal of the therapy (MOH, 2006; HAPCO, 2006).

For success and effectiveness of the therapy, individual factors related to the patient taking ART, like understanding the nature of the therapy can contribute a lot. According to Horizons/population council, (2004) the more patients understand about relationships

between treatment, adherence and successful outcomes, the better they do on treatment/therapy and the vice versa.

In general, FHI (2005) cited in HAPCO (2006) has categorized the needs of all PLWHA and their families under four interrelated domains as: need for medical service related to treatment and information, psychological needs, socio-economic needs, which are related to welfare provision, including human rights and legal needs, which encompass access to care and protection against violence and discrimination. It also asserted that addressing these needs in an organized and complementary manner among different stakeholders will prove the efficiency and effectiveness of provision of comprehensive care and support provided to people infected and affected by HIV/AIDS which in turn improves the quality of life of these groups of people.

Conceptual Framework

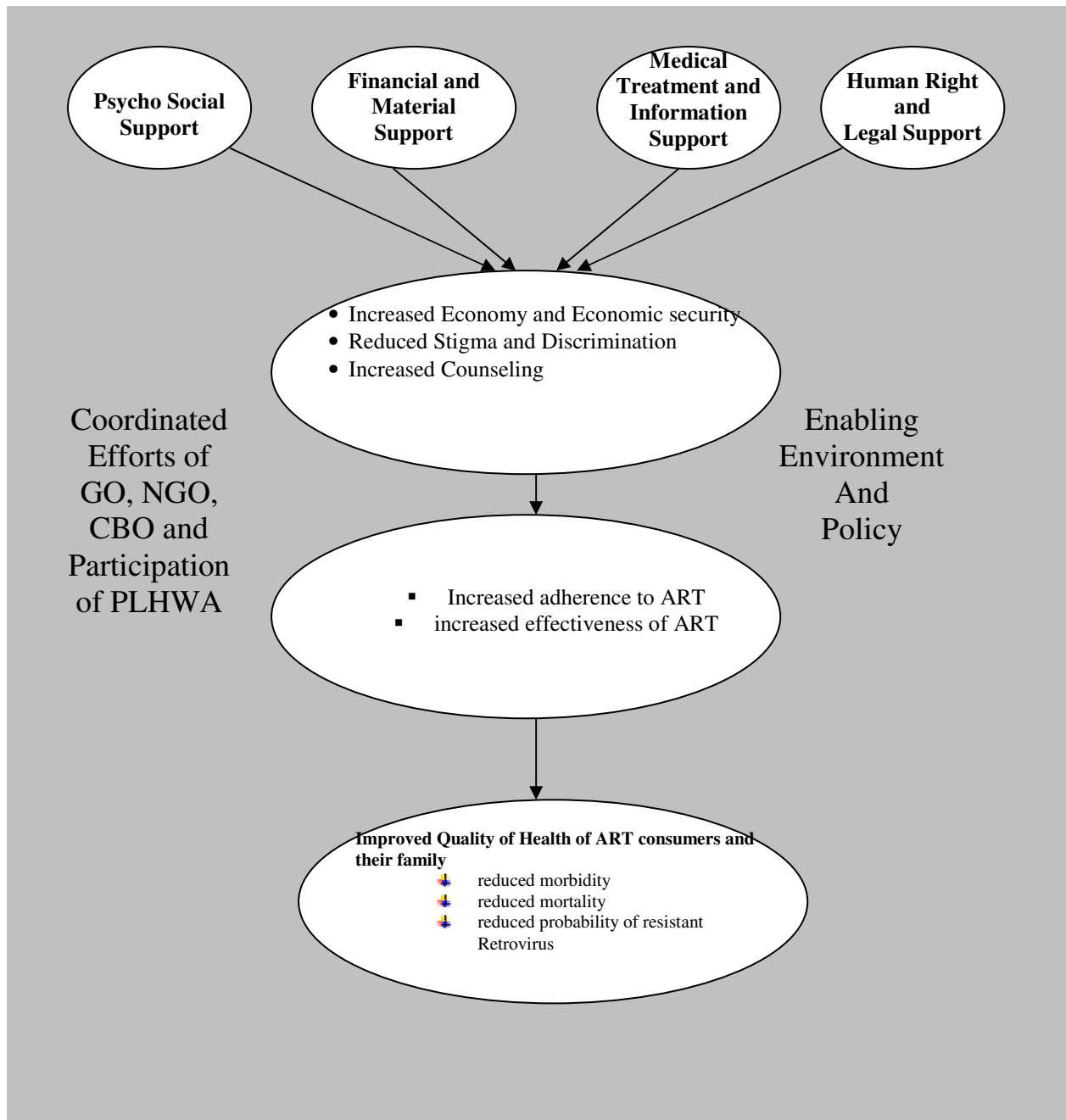
The first theory reviewed in this study is the Health Belief Model (HBM) which explains and predicts preventive health behavior, health-related practices and participation in health services (Rosenstock, 1974). Rosenstock (1974) also argued that what people believe about a (health) condition or behavior determines what they will do about it.

However, this model does not fit to this study because it mainly focuses on the behavioral aspects of individuals' health-related acts, which is not applicable for this study. Nonetheless, the concept of health-related practices of the HBM related to participation of PLWHA in perceiving the importance of the therapy has given some insight for the development of a conceptual framework that has been adopted by the researcher, to be used for this specific study.

WHO has introduced the Comprehensive Continuum of Care Model (CCoCM) in the provision of clinical and non-clinical components of care that enable individuals who obtain an HIV diagnosis to receive a comprehensive and inter-linked care from different domains of

care provided from peers, family, community/community organizations, GOs, NGOs, and health service providers. However, except at the peer support and home care domains, other domains of the CCoCM do not specify who will provide the care and how the linkage among the different domains is maintained. It also overlooks the participation of PLWHA in the continuum of care and importance of enabling policy on the issue (WHO, 2000c) as cited in (ICRW, 2004).

This conceptual frame work which is developed based on the CCoCM is used in this study to assessing and analyze the gaps of responses from different domains and existing needs of HIV patients, the researcher had chosen this model and used it as a base to adopt a conceptual framework (WHO, 2000c) as cited in (ICRW, 2004).



In this study, the researcher has assumed that supports provided from domains pertinent to psychosocial, financial, material, and medical treatment/information results in increased economic status. In addition, access for continuous counseling and human right support can facilitate the effectiveness of the therapy and reduce stigma and discrimination respectively.

A coordinated effort of GOs, NGOs, CBOs, as well as availability of enabling environment and policy is also assumed to facilitate the provision of a comprehensive care

to PLWHA who consumes ART. Consequently, this conceptual framework is used in this study to analyze the needs of ART consumers and existing responses provided from different domains of care and support stated on the conceptual framework.

Chapter Three

Research Methodology

Research Design

The study has employed a cross-sectional study design, and is qualitative in its nature. It also describes and explains the needs of AIDS patients who take ART and live in Addis Ababa Kolfefe Keranio sub city, Kebele 02/03. The main target of the study is to assess the needs and explain its relation with the economic background of participants. To this end, the study deployed a qualitative method of data collection tools of in-depth interview and observation. The data is presented qualitatively using description. However, a quantitative presentation of data is applied on presenting the background of the participants through tables that employed frequency and percentage. This is done to maintain clarity of the background data of the participants.

Study Site

The research site for this specific study is one of the biggest sub cities of Addis Ababa, Kolfefe Keranio. Addis Ababa is the most populated cities situated at the heart of Ethiopia with an estimated population of 2,145,418 (CSA, 2006). The city has ten sub cities including the main target of the study, Kolfefe Keranio sub city particularly kebele 02/03. Kebele 02/03 of Kolfefe keranio is a Kebele from where most of the residents including those from the neighboring kebeles receive free ART service from Alert hospital. Alert hospital is serving residents of this catchments area including neighboring Nifasilk/Lafto sub city.

The recent reports indicate that around 688,061 people reside in these two sub cities of Addis Ababa (CSA, 2006). Among the residents living in these two sub cities, total of 3,583 people have ever started ART by the end of 2006 (AAHB, 2006). This hospital, which is remarkably known for providing service to leprosy patients and people with skin disease

problem, is also a center for training personnel in all aspects of leprosy with especial emphasis to treatment, and rehabilitation applies to Africa since 1965. It used to be funded by non-governmental organizations (NGOs), especially of German's, until the federal democratic government of Ethiopia, MOH has taken the responsibility of administering it since July 2002.

Besides its longer experience and familiarity in the aforementioned services, Alert hospital is becoming prominent for services delivered around ART to AIDS patients in Addis Ababa as compared to other service providing hospitals in the metropolis. The hospital has started providing free ART service since January 2005 with the support it has obtained from INGOs until the federal MOH started to provide free ARV drug in June 2005(AAHB, 2006).

The location of the hospital is southwestern outskirts of Addis Ababa where the area is known for the name '*Koshe Sefer*', a name given for the surrounding area where the municipality of Addis Ababa discharges the dry waste of the city.

Study Population

The target population of the study are residents of the Kolfe Keranio sub city particularly PLWHA who are taking ART in Alert hospital. Among the residents of the kebele 02/03, the study specifically focused on those receiving ART service for free from the Alert hospital. Among an estimate of 3,583 residents receiving the service only 20 ART consumers who started the drug three years back were included in the sample. The participants included all categories of PLWHA ; male and female, young and older.

Participants Selection Procedure

Based on the objective of the study, the sample selected included PLWHA receiving ART from both sexes. Among the consumers of the service, a total of twenty (ten male and ten female) participants are purposely selected for the in-depth interview on the basis of years of experience (between one month and three years) they have taken ART in Alert hospital.

The objective of the study is to assess the need of ART consumers with diverse socioeconomic and demographic background. So as to respond the objectives, those residents of the *kebele* who have made at least a month and at most three years were identified. Finally, a total of 20 participants were purposively selected among those willing to take part in the study and able to forward necessary information in relation to the objective of the study. The participants were approached through the familiarity of the researcher to Alert hospital ART coordinating office since he was assigned to conduct field practice class at John's Hopkins university Alert hospital referral site. The coordinator of the referral site has also contributed a lot in helping the researcher in identifying and approaching the participants.

Sources of Information

This study included both the primary and secondary sources of information. The primary data was collected from 20 participants using in-depth interview guide. To authenticate the primary data, secondary sources of information mainly published reports by AAHB and MOH were used to generate data related to number of ART consumers at hospital and national level among others.

Data Collection Methods

The assessment of the needs of ART consumers requires comprehensive information. For this reason, the qualitative data collection method was used to gather the primary information. Even though main target was the qualitative data, the quantitative data was used to compute the statistical results of background of the participants. The instruments used to generate primary data were in-depth interview guide and personal observation guide of over all service provision.

A. In-depth Interview Guide

The interview was conducted with the 20 respondents including both male and female with equal proportion (ten male and ten female). The researcher has conducted the interview with participants after securing a verbal consent from managements of ART coordinator of Alert hospital through official support letter secured from Addis Ababa University and obtaining willingness of the participants. Then data was collected from twenty interviewees through one-to-one (face-to-face) interview at their homes.

To facilitate the discussion, semi-structured interview guideline with list of questions referring to their needs was used in the interview. The main focus of the interview guide is about needs of ART consumers and reasons that lead them to weak adherence towards taking ART drug as well as the relation ship between their major needs and causes for weak adherence, and their economic condition. It also contains issue related to need difference that evolve because of gender difference of participants..

B. Observation

Observation sheet was prepared to record or gather information on the surrounding environment, personal and environmental hygiene, housing conditions and the physical appearance (body build) of ART users.

C. Review of Existing Data

The primary data collected using above methods of data collection was substantiated reviewing the secondary sources of information. The materials that were used in this case include both published and unpublished reports from AAHB and MOH besides yearly reports on AIDS in Ethiopia.

Procedures of Data Collection

After the submission of the research proposal to the School of Social work, the researcher approached ART coordinating department head of Alert hospital. The researcher has taken support letter from the School of Social Work. The researcher also has met with the staff in Alert hospital to explain the nature of the study and the study procedures in which the time required was discussed. Approaching management of Alert hospital and participants of the study was easily realized since the researcher was assigned there for field placement course provided by School of social work.

Then after, the researcher has discussed with participants in order to get their consent and finally secured the participants informed consent. The final step for data collection was making actual interview with participants by tracing the guide for interview and putting the necessary information on the observation sheet.

Data Analysis

The qualitative data, procured from primary sources of information using in-depth interview, and observations are presented in different categories based on themes identified on the bases of similarities and differences of response obtained from participants of the study. Analysis and presentation of data was held after transcribing and organizing the data.

Prior to analyzing the data which was collected using in - depth interview, and observation, presentation of major findings based on different categories were made according to homogeneity of responses obtained from participants. These categories include participants' needs, challenges, opportunities, and other similar issues found in this study. After describing the findings, intra and inter category analysis was made based on the themes of analysis. The findings of the study is presented before the analysis which include the socioeconomic and demographic background of the participants. The demographic data focused on participants' age, sex, religion, source and amount of income as well as their marital and educational status.

The socioeconomic data was all about the source and amount of income per month, length of time since on ART, and employment status. Next to the background, major needs of ART consumers, challenges, opportunities, success and apprehension around the service are presented.

Moreover, data on themes related to economics, sex, and source and amount of income of participants are used to analyze the relation they have with major needs of ART consumers. In presenting the data related to backgrounds of the participants, tables that show different relations between male and female interviewees are presented using percentage and frequency. The tables that show the background data are also followed by descriptions with the purpose of increasing the clarity of presentation of the data. For the presentation and numerical analysis of the general backgrounds of the respondents, simple manual calculator is used.

Ethical Considerations

This research was conducted based on the verbal consent obtained from managements at ART department of Alert Hospital and John Hopkins's University Alert Hospital ART site coordinator through a support letter accessed from Addis Ababa University, school of Social work. The researcher has conducted this study keeping all ethical standard of a research. Participants of this study were first briefed about the purpose and nature of the research and were asked for their informed consent to involve in the study. The researcher has communicated them about their right to quit or not to involve in the research up on any inconveniences. Issues related to confidentiality and privacy have been also told and assured to participants of the study by the researcher.

Contributions of the study

This study is conducted with the purpose of assessing felt and experienced material and social needs of PLWHA who receive ART service. Therefore, the finding of the study will

have contribution in identifying some of the major challenges faced by ART consumers in the life long therapy they receive as it tries to provide up to date information about the situation of ART consumers and challenges they faced. Besides, the study will indicate possible areas for social work interventions and practice as it tries to attempt in revealing the real situation of ART consumers on issues related their major needs and gaps they experience including challenges they have encountered which deterred them from adhering to the therapy. On top of these, the study will contribute in recommending areas for further research. Hence, it will serve as a base for interested researchers in identifying issues related to the research topic.

Limitations of the Study

ART provision is relatively new care and support method to AIDS patients, which is launched since early 2005 in very few governmental hospitals in Addis Ababa including some regions of the country (MOH, 2006). Hence information, which participants of this study provided may not be to its depth. In addition, level of education of participants might have limited the quality of data provided from them, which in turn affects the result of this study. Since the study is conducted only on 20 participants who are purposely selected from ALERT hospital, the result cannot be generalized to population of ART consumers either in Alert hospital or in Addis Ababa.

Chapter Four

Findings of the Study

General Background of the Participants

At this part of the study, the researcher has tried to present data about participants' general background related to age, sex, marital status, level of education, length of time since they started ART, employment status, source and amount of income. Attempts have been made to assess the relationship between employment status as well as amount of monthly income of the ART consumers and their major need. The background of the participants is presented quantitatively using frequency and percentage tables with a sole purpose of vividly presenting the interviewees' background.

Those data, which are not related to backgrounds of the participants, are described. These include: enabling environments for taking ART as a life long therapy, major needs on adherence, gaps of responses provided from family, GO, NGO, CBO and the society is totally presented in description. This is done based on categorized themes and identified differences as well as similarities of response procured from the participants of the study. The major data, which is gathered from participants using in-depth interview, is complemented by data gathered on physical status, home and environmental conditions of the participants. by employing a one time observation conducted simultaneously with the interview.

Table.1 Age and Sex Distribution of participants

Age categories	Sex				Total	
	Male		Female			
	Frequency	%	Frequency	%	Frequency	%
Below 24	1	5	2	10	3	15
25-34	4	20	7	35	11	55
35-44	5	25	1	5	6	30
Above 45	-	-	-	-	-	-
Total	10	50	10	50	20	100

The data presented on table 1 shows that three participants (two males and one female) is 24 and below. Eleven participants (four males and seven females) are found between 25 and 34, while the rest six (five males and one female) of the participants are between thirty-five and forty-four years of age. Based on the data procured on about background of the interviewees, the range of their age is 23.

Table.2 Sex and Religion Distribution of Interviewees

Religion	Male		Female		Total	
	Frequency	%	Frequency	%	Frequency	%
Christianity	7	35	9	45	16	80
Islam	3	15	1	5	4	20
Total	10	50	10	50	20	100

The data collected on religious background of the participants show that sixteen (seven male and nine female) are Orthodox Christian while the rest of them four (one female and three males) are Muslims.

Table.3 Distribution of Sex and Employment Status of participants

Employment Status	Employment status				Total	
	Male		Female			
	Frequency	%	Frequency	%	Frequency	%
Employed	4	20	2	10	6	30
Unemployed	6	30	8	40	14	70
Total	10	50	10	50	20	100

The background information of the participants reveals that 14 of them do not have regular employment in any governmental or private organizations. Among these fourteen, six of them are males while eight are females. Further more, four of them have no permanent income except assistance from an NGO in their locality. Among these unemployed interviewees, ten of them earn their subsistence by engaging in laborious work and petty trading. The rest six (four males and two females) of the total interviewees are employees of governmental and private organizations as a result they earn a monthly salary working in these organizations.

Table, 4 Distributions of interviewees by Sex and Level of Income

Monthly income	Employment status				Total	
	Male		Female			
	Frequency	%	Frequency	%	Frequency	%
0-100	1	5	-	-	1	5
101-200	-	-	1	5	1	5
201-300	3	15	3	15	6	30
301-400	3	15	3	15	6	30
401-500	2	10	2	10	4	20
501-600	-	-	1	5	1	5
601&above	1	5	-	-	1	5
Total	10	50	10	50	20	100

Among the participants, who have involved in the in-depth interview, only one participant obtains less than 100 Birr per month and another one interviewee earns between 101 and 200 Birr per month. The income of six (three males and three females) lie between 201 and 300 and other six (3 males and 3 females) participants earn between 301 and 400 Birr. Four (two males and two females) of them earn between 401 and 500 while one female participant earns between 501 and 600 Birr per month. Only one male participant earns more than 600 Birr per month. The minimum and maximum amount of Birr the interviewees earn per month is 70 and 996 Birr per month respectively. As presented on the table, both male and female interviewees have limited access for monthly income.

Table.5 Distribution of Participants by Sex and Marital Status

Marital Status	Sex				Total	
	Male		Female			
	Frequency	%	Frequency	%	Frequency	%
Single	4	20	1	5	5	25
Married	2	10	3	15	5	25
Divorced	2	10	4	20	6	30
Separated	-	-	-	-	-	-
Widowed	2	10	2	10	4	20
Total	10	50	10	50	20	100

The data procured on backgrounds related to marital status of the interviewees show that six of the participants (two males and four females) are divorced, four (two males and two females) are widowed, other five of the interviewees (two males and three females) are married while the rest five (four males and one female) are single.

Table.6 Distribution of Sex and Educational level of interviewees

Level of Education	Sex				Total	
	Male		Female			
	Frequency	%	Frequency	%	Frequency	%
Illiterate	1	5	5	25	6	30
Grade 1-4	-	-	1	5	1	5
Grade 5-8	3	15	1	5	4	20
Grade 9-12	5	25	3	15	8	40
Grade 12+	1	5	-	-	1	5
Total	10	50	10	50	20	100

Among the total twenty participants, six of them (one male and five females) are illiterate. Only one female participant has elementary education. In addition, four (three males and one female) of the participants are educated at junior high school level (grade 5-8). Furthermore, eight (five males and three females) have attended high school education (grade 9-12) while one male participant diploma in auto mechanics.

Table, 7 Distribution of Sex and Period of Time Since Participants Commenced ART

Length of time since interviewees commenced ART by month (inclusive)	Male		Female		Total	
	Frequency	%	Frequency	%	Frequency	%
1-6	1	5	2	10	3	15
7-12	-		1	5	1	5
13-19	4	20	4	20	8	40
20-26	5	25	2	10	7	35
27-33	-	-	1	-	1	5
Total	10	50	10	50	20%	100

The data on table 7 shows that three participants (one male and two females) are found in the range between one and six months, while one participant is found with in the gap of seven to twelve months since they started ART. Eight participants (four males and four females) and other seven participant (five males and two females) including, the rest, one (female) participant are found with in the gap between 13 and19, 20 and 26, and 27and 33 months respectively. In addition, the data on table 7 depicted that the range referring to length of time since participant commenced ART to be 17 months. For further information see annex I.

Findings on Major Needs of ART Consumers

The findings regarding major needs of ART consumers are categorized in to four major themes. The first part presents the enabling environments including experienced major needs (both material and social) of ART consumers. The second part deals with support provided from and gaps on CBOs, GOs, and NGOs in addressing the major needs of ART consumers. Furthermore, level of involvements, membership and social exposure of participants of the

study in community associations was discussed in the third part of the finding. The fourth part of the finding tries to present experienced need related causes for weak adherence and felt issues and gaps identified by the interviewees for future intervention are presented.

Enabling Environments of ART consumers

Almost all, eighteen of the participants out of the total twenty, have disclosed that one of the major enabling environments that facilitated their health is the presence of ART care for free at a hospital which is found in their near by community. In addition, availability of medication and treatment for opportunistic infections including access for adherence counseling were stated by fifteen of the participants as major enabling environment. For instance, Among them a 28 years old woman participant states the situation saying that,

The availability of the medicine for free to HIV infected citizens like me is one of the major enabling environment .What is more, is the presence of free counseling service in general and adherence counseling in particular.

However, the rest two female participants have reported that there were no enabling environments for taking ART. They argue that accessing ART is not a solution in sole unless the community including their family members stops discriminating PLWHA, like them. A participant living with his family stated,

My family members blame me for contracting HIV/AIDS because they think that I contracted the virus because of promiscuous behaviour they attach to me. They also separate the materials I use in the house including glasses I use for drinking water. The society is not different from my family. Many of my friends do not want to associate with me because I am living with the virus and they think they will be identified as HIV positive if they associate with me.

The information collected from participants of the interview also shows that sixteen of them have stated that the presence and support provided from their husband, wife, children and/or generally people they live together as the enabling environment that contributed in facilitating their health to the better situation and improved adherence too. A woman with 28 years age described this situation saying,

the presence of my three children, who are currently living with me, is a cause and great support for me to take ART with energy and hope because they provide me with the necessary care and support.

In connection to this, six of the participants have also stated that the availability and support of *iddirs* (burial associations) in providing referral letter to the local *Kebele* officials to easily access residential identification card that can be used to register at the hospitals to qualify free ART service. The participants reported this situation as a step forward to the enabling environments in taking ART as a life long therapy. Furthermore, presence of some good mannered, friendly, cooperative and humanly health professionals at Alert Hospital were stated by four of the participants as an enabling environment.

The data also shows that among the total twenty participants, seven of them have stated that availability of referrals to service providers by the hospitals to NGOs, which provide financial, food, and psychosocial support as one of the enabling environments that facilitates the intake of ART as a life long therapy. In addition, two participants have said that the provision of education about the importance of ART through media and health professionals on issues related to sticking to the time for taking ARV drugs, its potential side effects and importance of adherence as enabling situation.

Many (seventeen) Participants reported that they live with their family members. These include their fathers, mothers, sisters, brothers and friends. All these participants, except one, have stated the significant care and support they are receiving from members of their family. They further stated that they have disclosed their sero status at least to one member of their family so that the people who knew their sero status provide them with financial and moral support. Furthermore, they stated that people, they live with, are supportive in reminding them the time for taking the medicine, preparing food and helping them in their daily routine.

Underlining this fact a divorced 31-year-old woman stated, “A year ago, I was seriously sick and I was not in a position to help my self in cooking and taking food by my own. By then, it was through my son’s hand and help that I used to take tablets and food and became relatively well.” She also states the loving and caring personality of her son, which usually made her feel important. She further stated;

My son is the only reason for me to dream and aspire of living tomorrow. In addition, he is also the reason for the decision I made to take ART. I cannot think of my life with out him. He is really doing his best to support me so that I can live healthier and lead a relatively relaxed life. However, I fear that he might be living with the virus too. Until now I could not convince my self to check his status since all my life becomes miserable if the result of the test turns positive.

Only one participant has disclosed the challenges he had because of living with members of his family since they do not support him. He said that instead of support, they frequently blame him for contracting HIV/AIDS because they think that it is because of his promiscuous behaviors that he contracted the virus. The rest three participants lead a lonely life. Two of them have disclosed the challenges they encountered in not having some one, who can assist them at times of sickness and provide them with moral support. They even stated that their loneliness, having no one beside makes them think only about their ill health. However, one of the three participants, who lives lonely, stated that he is very happy with his life because he is free of worries related to disclosing his sero status and taking his medicine freely with out fear related to the presence of people in his home.

Major Needs of ART Consumers

Despite the enabling environments, which the participants stated, there are a number of major needs that were revealed by ART consumers. According to the information gathered from twenty participants, sixteen of them stated that they have a major need for nutritious food. Fourteen of these participants explained that they are unemployed and have no permanent job from which they can earn money that can be used to cover the expenses of

their need related to either nutritious or simple available foodstuff. Among the fourteen unemployed participants, eight are women and the rest six are males. Other two male participants have also stated about challenges they have encountered in accessing enough food especially of nutritious one, stating that the salary they earn is not enough to cover their food and related basic needs

In addition, three participants, who access food support from a nearby NGO explained that the monthly food support they obtain was not enough to meet their own and their family members. A pregnant participant stated this issue more vividly explaining,

One of the major challenges I have faced, together with my family is that ,the food we are supported by Medhin Social center (MSC) together with little amount of money that my husband makes through petty trade is not enough to cover the food need of my family. As you can see me, I am pregnant and have no strength and good health to do some works of my skill. I some times take the medicine with out food. That is really a terrible choice to be taken, but it is common for me and my husband to take the medicine with out nutritious food and/or any ordinary type of food.

Three of these participants have also said that their unfavorable health situation, and stigma and discriminations forwarded from the community have negatively contributed in affecting them not to involve in any type of work that lead them generate income to be used for covering their food and other needs. A twenty-eight years old male participant stated the challenges he faces as a result of stigma and discrimination saying,

because many people around my village knew my sero status, they do not want me to work in their firm. I used to work in a metal workshop. However, because of rumors my employer heard about my HIV positive status, he has fired me saying that his firm has no market and he promised me to call me when the business blows. Nevertheless, the case was not that. It is because I am just living with the virus and he has feared that he will be infected with HIV/AIDS if he works with me.

The data also indicate that almost all of the participants have reported about challenge they face in renting houses from private owners because of discrimination and stigma .They further explained challenges they have in covering the cost of money paid for the houses they rented. On top of these challenges, many of the interviewees and focus

group discussants have stressed the need they have for accessing their own private houses or kebele owned ones.

However, some participants have said that an NGO working in their community is providing them with a monthly support of 70 Birr to be used for covering house rent expenses. However, all of these participants reported that they do not have personal privacy to take their medicine freely. They also stated that they hide the box/case of the ARV drugs not to be identified by their renters so as to minimize the risk of being fired from the house they rented and are living in. Two participants expressed their worry related to contaminating members of their family, especially their children, with TB and related transmittable diseases as a result of living being more than three in a single roomed house that has no space and enough ventilation.

The data depicted that almost all of the participants (nineteen) have reported about the need they have in connection with societal love, respect and non-stigmatizing and discriminating acts/behaviors from the society. In line with this issue, a participant whose age is 28 said,

I need only real love, warm greeting and respect from the society I live with. I believe that the more I feel loved, respected by members of the community, the lesser the degree of frustration, anxiety, and stress I experience and the higher the value I attach to myself. I usually feel rejected and unworthy while some people pointed fingers at me and back biting me because of the sole reason I am sera positive.

One of the six employed participant reported, *“I suffered from frequent nagging and precaution forwarded from my employers at times I become absent or arrive late to work.”*

Differently to the idea stated above, a 28-year's old participant said,

Though, I have encountered no challenges from the society, the size and frequency of intake of the medicine is a bit challenging because it bores me up and gives me a hard time.

The data further revealed that many of the participants(eighteen), among the total twenty, have said that they need the society to support them by avoiding discrimination and

providing care and support to PLWHA like them including their children by covering their need related to food and educational materials. In addition, six female-headed family leaders, who involved in the in-depth interview and, have stressed the importance of meeting moral and material needs of families led by females like them to reduce the burden of responsibility. They further stated the importance of support the society might provide them in terms of provision of real love, respect, both social and material support than discriminating them and their children. However, a 28 years old pregnant woman has a different view of the society's attitude towards people living with the virus. She argues that the society has now shifted from discriminating PLWHA and is rather appeared supportive in different ways. She further states,

The time for pointing fingers at PLWHA has already passed and I don't see as such exaggerated discriminatory acts forwarded from the society. Though I do not personally expect any support from society, I expect their involvement in real and ethically furnished volunteerism to help and support those PLWHA, who have nobody besides them to provide care and support.

Gaps of Response from GOs

Almost all of the participants have stated that free ART provision is one of the major responses operated by the government. They have also added that this free treatment and medication is provided to them in a nearby hospitals found in their catchment area. However, two of the total participants said that they have obtained nothing from the government as a support even if they have discussed that, they are receiving ART service for free.

Gaps of Response from NGOs

Concerning support they have from the NGO sector, many (twelve) of the respondents have stated that this sector is not working well and reducing their challenges because of different reasons like: inconsistency, lack of identifying their real needs and lack

of resources in addressing their real needs. However, four of the participants depicted that they obtain 70 birr financial support to be used for renting house, 45 Kg of wheat and 3 liters of oil per month from a near by NGO called Medhin Social Center (MSC).

Few (Four) participants who are supported by MSC stated that the level and nature of support they obtain from this NGO is not enough and is inconsistent. Few of the interviewees and the focus group discussants have also asserted that these organizations should see a way to make people reliant through the support rather than providing support that do not lead to self-sufficiency and reliance.

Response from CBOs and the Community

Some (four) of the participants stated that CBOs like the iddir has helped them in identifying potential organizations that can provide different types of support. This is done through referral they make to a near by NGO and in writing them a support letter to kebele offices for accessing Identification (ID) card which later helped them for accessing free ART service since hospitals do not provide free ART unless one has an ID.

Differences of Needs among Female and Male Participants

The data obtained from participants reveal that access for job as a pressing need for males than females. All the male discussants and two interviewees have stated that access to job as a pressing need for men than women since it is not common for the former to sit ideal at home. They confirmed the need males have for jobs as a pressing agenda that has to be quickly met as compared to their female counterparts since it is not common for the males to stay ideal at their home with out jobs.

The data collected from ten female participants depicts that two of them have stressed the need for safe environment and house that has the potential to protect any possible harm on women to be their different need. Few(three) female participants have

explained the opportunity of being given priority in accessing health services at times they visit health posts as a major needs of females, females have different reproductive work responsibilities besides the biological difference they have in terms of strength as compared to males.

The need for presence of female care provider in the family (especially wife) was reported to be a different need males exercise as compared to females. This was reported by three male participants (two divorced and one widowed) by reasoning out that they believe females are important in meeting their need related to care and support provision for themselves including their whole family.

However generally, many (14) of the participants, both males and females, have reported that they do not exercise any difference in terms of need between male and females ART consumers. They think that both of them (male and female ART consumers) have similar needs as their challenges and statuses are of similar type.

Causes for Weak Adherence to ART

Many of the participants of the study stated a number of causes that forced them to delay taking the regimen on time, because of failure in meeting the needs triggered in relation to food and other prescribed orders of the physician. Some of the major causes stated by participants based on the frequency of response from higher to lower include (1) involvement in long lasting social responsibility like mourning and wedding, (2) lack of financial support which can be used to cover the food and related needs that has to be responded in the process of taking ART as a life long therapy, (3) forgetfulness (4) unavailability of family member that reminds time for taking pills, and (5) long travel (journey) were among the causes discussed by participants of the study. Few (three) participants, have said that because of fear of stigma and discriminations forwarded from their renters of houses, they delay the time for taking ART in occasions where the member

of the family of the renters are around their home for any social reason . In addition, some (seven) unemployed participants who are labor workers said that the nature of their work is one of the major causes that adversely contributed to the delay in taking the medicine on time. They said that because of the attached stigma and discrimination, they do not take their medicine at their work place for not being seen taking the medicine.

Furthermore, participants reported that because of the tiresome nature of work they engage in, they sleep earlier and sometimes miss taking the medicine. The difficulty of taking the pills on time is best explained by female participant of age 28, who lived depending on food and financial support from an NGO reported,

It is devil which usually forces me forget taking the pills. You know, sometime the devil pushes me to quarrel with people including my husband and turns me crazy. After that, I forget to take the medicine and experience a feeling of unworthiness and hopelessness, which drives me to forget or consciously avoid taking the pills. However, the devil tempts me rarely. So, I take the medicine on time with the help of my son and my husband.

Involvements of ART consumers in CBOS

A total of twelve (seven male and five female) participants said that they are not members of any community-based organizations like 'iddir', 'equib' and community associations. Only one female participant of 28 years, who lives with her husband and her son, has reasoned out that lack of money to be paid for membership and monthly membership fee has limited her from being a member of iddir. However, the rest eleven have stated different reasons for not being member of CBOs. Among these: tedious nature of work they are involved in is stated by six of the twelve participants who are not a member of any CBOs while the other four have stated that they do not see any worthy accomplishment of the CBOs in reducing their need and challenges.

Some participants have also explained that CBOs are facilitating discrimination against PLWHA and their children. As a result of this, they stated that they do not want to

be member of CBOs fearing the stigma and discrimination they might face from members of the CBOs. Few (four) of the participants have stated that the nature of their work in making them tired so that they do not have any time to involve in community affairs.

Discussion

At this section of the study, the researcher has critically analyzed and briefly discussed the major issues related to the research objectives. The analysis is presented under four different sections. The first section deals with the relation between economic backgrounds of participants and their major needs while the second component deals with discussing existing differences of needs between male and female participants because of sex. The third sections of the discussion part of the study deals with need related causes for weak adherence to the use of ART. The final part of this section deals with the general opinion of participants based on their experience and the impact of ART on their health.

The Relations between Economic Status and Major Needs of Participants

The data from the in-depth interview depicts that those participants whose income is based on laborious work, petty trading and support from a near by NGO, and whose monthly income is less than 400 Birr have reported needs related to : (1) nutritious food and, (2) access to their own or *kebele* houses. In addition, the finding on the background data (monthly income and employment) exposed that some of the participants, who earn below 500 Birr per month and who have permanent employment, were also challenged with accessing nutritious and at times enough amount of food for themselves and their family members. They further pointed out about their unmet food need, which they believe has a direct link with their unemployment and ill health status that in turn affected the amount of income they earn from laborious or other type of work.

In addition financial and other supports few participants obtain from NGO that work around their community to be inconsistent, unreliable, and even not enough. On top of this limitation, they have reported that these supports are usually available only for bed-ridden AIDS patients rather than people like them who are relatively better in their health, but have no source of income or support. Hence, this data has implied that the amount of income

(economic status), which ART consumers obtain, and their need for nutritious and enough amount of food has direct relations regardless of source of income or employment status. In other words, when the amount of income interviewees obtain is limited, whether earned from regular employment, labor work and/or petty trade, they face challenges in regards to responding to their food, housing and other major needs and vice versa that can directly or indirectly affect the effectiveness of ART. The researcher's assertion is also found to be similar with the conceptual framework in that ART consumers should access financial and material support in order to adhere to ART. In addition, the result of the study has formed a link with the conceptual framework since the needs, which are found in the study, can be provided to ART consumers if there is only a coordinated effort of different organizations including families, peers and the community at large. The existing literatures presented by HAPCO (2006); WHO (2006); and Annania,(2002), where some of the major needs that should be met by ART consumers are cited to be need for nutritious food, clean house and environment among others.

However, participants who have a permanent job, have reduced tension about searching a job that enables them cover their daily food need, while those who have no permanent employment spend their time and energy seeking for jobs that enable them generate a daily income. Nevertheless, this argument emphasize that those participants who have permanent jobs do not face the same level of challenges related to accessing enough or nutritious food.

Those who have no permanent jobs might lead unpredictable and unplanned life with none of their needs met well. On the other hand, it is also important to see the level of mental satisfaction, and positive feelings, related to: sense of contribution, importance and belongingness exercised by those participants who have regular employment, whatever the

amount of income is, and mental tension and physical deterioration exercised by those participants who have no regular employment.

The data procured from the focus group discussants also confirms the stressful situation participants have experienced because of inaccessibility of job of their ability and skill added with discrimination attached to their HIV positive status. This is usually followed by, what many of the participants said, staying idle at home thinking and waiting only about time for taking the pills. This seems to imply the extent of negative feelings this participants may possibly develop as a result of their own account related to level of contribution, sense of belongingness and feeling of importance to them selves in particular and to the community in general. The positive impact of having permanent job can be expressed in terms of mental satisfaction and stability that possibly contributes for the effectiveness of ART, as compared to challenging situations and mental instability including stressful situations experienced by those who are not employed and earn daily income from labor work and petty trading. The reality, which the researcher has come out as an arguable point is the adverse impact of reported stigma and discrimination on some of the participants in terms of economy, social involvement and psychological make up. This analysis is made based on the data obtained from a large number of the participants who have reported challenges they have faced in relation to stigma and discrimination, which they related it as one of the causes for their unemployed status since many of them reported denial of their right to work, associate with any one, access service in equal position etc.

Those participants who engage in laborious works and petty trade lose more energy as compared to others who engage in 'easier' type of jobs. This, as a result, brings about the need for more food that substitutes energy that is lost through hard work besides its importance in building the body. The participants of the focus group discussion have also stated similar experiences as that of the in-depth interviewees. In addition, the researcher's

observation depicted weak body build of many of the participants of study and dilapidated, poorly furnished, unventilated and unclean houses of many of the participants. On top of this argument, the researcher has understood the importance of emphasizing on working towards responding to unmet needs of many of the participants which resulted from weak, at times, inconsistent nature of income they earn both from permanent and non-permanent jobs including unreliable and inconsistent financial, material and moral support from NGOs, CBOs, and GOs.. This is because leaving the needs unmet can negatively affect them from attaining their needs related to the therapy and attaining the maximum result out of the it.

Annania, (2002) and HAPCO (2006) have also capitalized the importance of coordinated efforts of stakeholders, which work on provision of care and support for PLWHA on top of meeting their nutritious food and other needs in order to bring about better results out of the treatment.

In general, the analysis stated above has implied weak economic status of ART consumers has direct relation in limiting many of the participants from addressing their major needs because many of them are in a situation where they cannot meet one of their basic needs i.e. food. Hence, it is possible to make assertion that weak economic status of almost all participants is directly related to many of the major needs identified in this study, which, in turn, affected the efficiency and effectiveness of the ART on participants or limited participants from achieving the maximum one can gain from receiving the therapy.

Furthermore, high expense attached to nutritious foodstuffs and house rent fees have implied to bring adverse effect on participants in the process of meeting their major needs. PIH, (2004) argues in similar pattern that malnutrition and lack of access to nutritious food can bring about negative consequences on the health of ART consumers. It added that the economic status of ART consumers might affect the effectiveness of ART since patients, who have no access to resources, do not easily access food of their choice and do not have

the opportunity to meet their major needs, which are important for the effectiveness of ART. Specifically, unmet needs that are related to food opens the opportunity of weakening the success and positive results one can obtain from ART. This is because nutritious food builds the body of patients and hence reduces the replication of retrovirus in the patients' body. Contrary to this, not responding to nutritious food can lead the patient to be affected by different OIs since he/she lacks resistance and antibody, which protects the body from easy attacked by diseases. Therefore, the conceptual framework fits this study in identifying one major domain of support to be provided to ART consumers for maintaining or improving adherence ton ART which in turn results in reducing mental and physical deterioration of AIDS patients.

However, in this study, few participants have stated that they have no problem in addressing their needs related to food including nutritious one and needs for houses. This might be because of relatively high amount of money they earn, or support they have from their family members or other organizations. WHO, (2006); HAPCO, (2006); FHI (2005) & MOH, (2006) asserted the importance of financial, food, and psychological support in helping PLWHA address some of their needs.

One of the needs, which is found to challenge the participants, is human right or legal need. The challenges of stigma and discrimination posed on participants by their house renters, neighbors and the community is found to facilitate participants' need related to human right and justice. MOH, (1998) asserts the importance of respecting the rights of PLWHA in reducing the rate of spread of HIV and address their need for human right and legal protection as equal as any individual.

Based on the finding on human right and legal needs of the participants, the researcher has realized the importance of urgent mechanisms of educating the public about the virus, how it transmits ,and how stigma and discrimination forwarded on PLWHA

perpetuates than avoid the problem. Hence, social justice should be put at the forefront of options designed for intervention because any intervention that marginalize social justice, equality and disadvantaged groups of the society fail from addressing the needs of any group of society.

Differences of Needs between Female and Male ART Consumers

The study has represented equal number of participants in the study (ten male and ten female) in order to assess possible need differences that might exist because of participants' difference in sex. Hence, based on the data obtained from the participants, the researcher has assessed, identified, and presented few differences that were experienced by both, men and women, participants because of their difference in sex. Accordingly, one of the issues, which was found in this study is access for needs related to job as a pressing need for men than women. However, it seems to emerge as a unique need of males because of the level of awareness participants have on gender equality and level of education to critically analyze differences besides their exposure to traditional gender roles. FHI (2005) argues the importance of economic support, which encompasses supporting PLWHA, both males and females to have access for jobs of their skill.

Moreover, asserting employment/job pressing for males as compared to females abuses the rights of all individuals have for access to all forms of support with out discrimination National Policy On Ethiopian Women (NPOEW, 1993).

On the other hand, the finding indicated that the need for safe environment and house, which has the potential to avoid any possible harm or violence on women to be the different need expressed by some female participants. They reasoned out that need for safety within the home environment can reduce the exposure to sexual harassment and other violence. This can be seen from the disempowered position of women and act of violence forwarded from men using the exposure of women to vulnerable environments and houses.

This also implies the need for safe environment and house as a different need to be met to females as compared to their male counterparts. Generally, the study has indicted few differences on needs of ART consumers because of their difference in sex. However, the result of the study has revealed that there were no major differences, which come out as a result of being male or female ART consumer.

Relation between Need and Causes for Weak Adherence

The finding part of the study reveals that many of the participants are encountered with major needs that are related to income, nature of work, need related to significant other and social responsibility (mourning and wedding ceremonies), and long travel (travel out of cities for different purposes) as major causes for weak adherence. In addition, limited income, which many of the participants obtain, has weak purchasing power and is found to have adverse contribution on adherence to ART by many of the participants. Hence, based on this finding, it is possible to assert that limited income, long lasting and monotonous nature of work that participants are involved in, including social responsibilities like weeding and mourning, and absence of significant other have direct negative consequences on adherence to ART by participants. Castro, A (2005) also asserts the financial constraints, stigma and discrimination, travel, problems at work place, unemployment, and religion as factors that adversely affect ART adherence among ART consumers.

Longer hours, which respondents spend on fulfilling social responsibilities and inconveniences of social events (wedding mourning) and the public exposure has been some of the constraints that are found to affect adherence. Not taking the pills at the allocate time and with prescribed food was reported by many of the participants to limit their adherence. These data has implied that problems related to taking pills at the prescribed frequency and time in is negatively contributing to weak adherence by many of the participants since one of the elements that have to be fulfilled for maintaining adherence to a therapy is regular in

take of ARV drugs. PIH, (2004); Population counsel (2004) & WHO, (2006) asserted the contribution of sticking to the ART-drugs for better adherence and the vice versa.

WHO, (2006); MOH (2006); HAPCO (2006) and FHI (2005) argue the importance of nutritious food, significant others and continuous counseling in achieving better adherence among ART consumers besides the importance of sticking to ARV drugs.

Chapter Five

Summary of Major Findings

A qualitative research method is applied in order to assess the major needs and causes for weak adherence of Art consumers in Alert Hospital. To this end, the study has used in-depth interview, and observation of the researcher to collect data from 20 people who are purposely selected for the study.

The result of the study has revealed that one of the major needs of participants of the study is nutritious food. Need for shelter (houses), employment, and social justice/human right are major needs that are revealed as a result of the study. In addition, the study has come up with the need for prior access to health services at health posts and safety within the home environment as distinct needs of women. On the other hand, the result has shown that male participants need access to non-domestic works and presence of female care provider in a family as compared to their female counter parts.

Furthermore, based on the assessment made on the monthly income and access to support from families and NGOs, the study indicated the economic status of the participants having adverse contribution to weak adherence to ART. It is also found to limit them from addressing their needs related to nutritious food and houses having privacy, which further ruin participants' adherence to ART.

The result has revealed some of the major need related causes for adherence based on self-report of participants. Hence, stigma and discrimination related to needs for social justice),forgetting (need for support from family),social responsibilities(like wedding and mourning ceremonies) and need for access to nutritious food are found to be the major need related causes for weak adherence reported by participants. Need for social justice /human right, which resulted from stigma and discrimination, is depicted as the major need that

cause weak adherence. This is because participants are forced to escape from taking ART at the prescribed time if they are exposed to public gatherings to avoid stigma and discrimination. Generally, the study has indicated areas for social work intervention and further research.

Conclusion and Social Work Implications of the Study

Conclusion

This study, which is conducted to assess the major needs of ART consumers, has come out with different needs of participants that are mainly related to need for nutritious food, social justice/human right, employment, financial support, house that has privacy as well as need for conducive environment.

It was also found that weak economic status of participants, which resulted from their unemployment, lack of source of income and marketable skills, having an adverse impact in their endeavor to address their basic needs and as a result adhere to the therapy. The study has also revealed the adverse impact of economic status of participants in addressing the need for nutritious food and access to rented houses.

Female participants identified the need for prior access to health services at health centers and need for safety within the house environment. On the other hand, male participants have identified need for access to productive (non-domestic works) and the presence of female caregivers in a family. Differences on the needs of service by gender that evolved as a result of this study requires special consideration in order to effectively address the issues of male and female ART consumers. It has also implied the need for skill training to participants on areas of income generating activities inline with provision of education to the community around the intervention area about supports they should provide to them.

The results related to need for nutritious food and housing described above have also implied a social work practice that can address the root economic challenges of ART consumers which is planned in a way it can create opportunities for access to employment or income generation. One of the effective ways of doing this can be providing training on different skills to ART consumers based on their choices, interest, previous skill and capacity. Similarly, this program should incorporate provision of educational programs to the community at the target site so that the larger community will acknowledge and contribute by using skills and products of ART consumers. This inturn contributes positively to adherence to ART because it can increase the productivity of ART consumers and reduce by reducing stress and energy they lose. In order to make the program effective, it should be designed including provision of continuous adherence counseling and psychosocial support to ART consumers.

The results of the study that are related to participants' need for employment, social justice (the right to live with out stigma and discrimination) and access for shelter has implied a call for social work practice that focuses on prioritizing needs, assessing the strength within the participants as well as potentials that are found in the environment of ART consumers.

However, emphasis should be given in planning programs that do not expose ART consumers for further stigma and discrimination. Moreover, components of the program should incorporate an integrate support that can be provided from various sectors working on the issue. This can be done by involving individuals, family, peers, neighbors and the community at large as well as GOs, NGOs, and CBOs in the program so that a comprehensive program of care and support related to nutritious food, psychosocial, social justice, housing and employment will need to be put on place. It will also become strong if the program involves ART consumers and community members from the planning to

implementation stage of practice so that they will develop a sense of ownership and belongingness to the program by reducing their dependency.

However, unless the aforementioned program for social work practice is supported through provision of intensified education that focus on reducing stigma and discrimination on PLWHA, it will not be effective as desired. Therefore, designing possible ways for educating the community around the target site will contribute in addressing ART consumers' need for human right/social justice, which as a result gives them the opportunity to access other needs besides increasing the level of adherence to ART.

The researcher also believes that the enabling environments within the participants, which includes presence of significant others, their prior skills, and interest for having something to do among others should be underlined and attempted with the purpose of applying the strength based practice of social work.

Finally, the result of the study has implied the need for educating the public and ART consumers about social justice/human right issues. This can be best handled by social work professionals and organizations working on areas of social justice with the purpose of reducing abuses of human right and increases the participation of ART consumers and the community at large in the endeavor of controlling the impacts of HIV/AIDS. Generally, the results of the study has asserted the need for consorted effort of individuals, family, peers, community members, and the society including GOs, NGOs, and CBOs to work with a shared goal towards contributing to the better health and life of AIDS patients.

Area for Further Research

Data from different sources, for example WHO, (2006) and MOH, (2006) depict that ART is one of the responses given to the needs of PLWHA. However, the result of this study show that there are still other needs which are connected to social, human right and material needs of ART consumers ,which should be addressed if a comprehensive response

is required to address their needs. On top of this effective treatment of ART depends on adherence to medications besides properly following prescriptions related to food, hygiene, and support from family as well as the community including different organizations that work to bring about social justice.

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Annex I

Issues Discussed to obtain Consent

Good Morning /Afternoon:

I am here to discuss about the need (both social and physical) ART consumer have and related issues on enabling and challenging situations they have faced as a life long Therapy. Through the information you provide me, I am expecting to understand the major needs you have and differences you might be exhibiting interim's of need because of you gender, educational an socio economic stats, length of time since you resume ART among others. This data is only serving academic purpose and has no any other purpose to serve than producing a master's thesis and /or an article.

My study includes a total of 20 ART consumers. Among these, 20 (10 male and 10 female) will participate in the in-depth interview. All of the participants are patients who are currently receiving service from Alert Hospital and reside in Kolfe Keranio sub city kebele 02/03. Taking part in this study is on voluntary bases. You may choose not to take part or you stop answering these questions whenever you want to. There are no negative consequences from the researcher, Addis Ababa University and or /or Alert Hospital administration for not responding to this interview.

This study will keep your name and other necessary information confidential. For research analysis, individual responses to the interview questions will be added together, and the information from the study will be repented in summary. The information that I learn from this study will be available in a written report that will be submitted to Graduate School of Social Work.

You will receive a transport reimbursement of 25 birr which is aimed at compensating the time you share with me. If you have any questions you want to ask about the interviewer, you may call the Graduate School of Social Work, Addis Ababa University, at 251-11-6186441

Annex II

In-depth Interview Guide

The following are the basic questions I have prepared in order to find out data related to the needs ART consumers have (of both physical and social) in attaining their intended health goals. The questions are prepared base on the objectives set for the research.

I. Background of the Interviews

Sex

Marital status

Religion

Time ART commenced month _____year _____

Income per month

Source of income

Educational status

Condition of housing (rented private, own, rented government number of rooms) with whom he/she lives?

1. Would you explain the enabling environment that you experience in the process of taking ART as a life long therapy?
2. Tell me about the important issues of concern (need) that are currently met by different governmental and not-governmental organizations including CBOS
3. Tell me about the major constraints/challenges you have had as a consumer of ART.
(What are the major needs you feel that is unmet while you are taking the therapy?)
4. What are the roles of members of your family (husband/wife, children, sister/brother mother /father in helping you adhere to the therapy?
5. Would you explain the demands (needs) you fell or experience you might have because your gender is male or female?

6. Could you explain about the difference in gender in relation to ART usage and access for ones own need?

II. Need for maintaining adherence

7. Would you state the kind of support ART consumers, like you, need to be provided with in order to maintain adherence and better health condition?

8. Could you describe the facilities that existed (water pipe, number of rooms of your house ad availability of showers) in the house you live in?

9. Could you tell me with whom you currently live and explain how these people you live with or your loneliness have hindered or facilitated in attaining your loneliness have hindered or facilitated in attaining your needs (both physical and social) and social)

10. Would you tell me how your economic status had affected you in meeting your physical and social needs as a consumer of ART?

11. Could you tell me the kind of support you need from the society in relation to its importance for you, as ART consumer?

12. Would you deeply tell me the causes for non- adherence to ART regimen based on yours experience?

13. Can you tell me some of the major effects for your social stratum in relation to meeting your social and physical need you have felt and experienced?

14. What do you suggest to be done to ART consumer, like you, in order to help you adhere to Art?

15. What is your general belief and opinion on ART and its impact on attaining your health goal(s)?