Assessing Adherence of PLHIV to ART Treatment: The case of Yeka and Gullele Sub City in Addis Ababa

A Proposal on the CHBC Project

Lisan Atnafe: CHBC Project Officer
Anley Haile: MNCH project advisor
February 2013

Acronyms

AIDS	Acquired Immunodeficiency Syndrome
AMREF	African Medical and Research Foundation
ART	Antiretroviral Therapy
CBO	Community-Based Organization
CHBC	Community Home-Based Care
EPI	EP Info
FBO	Faith-Based Organization
FGD	Focus Group Discussion
HAPCO	HIV/AIDS Prevention and Control Office
HIV	Human Immunodeficiency Virus
IDI	In-depth Interview
NGO	Nongovernmental Organization
PLWHA	People Living With HIV/AIDS
SPSS	Statistical Packaging for Social Sciences
UNAIDS	United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WHO	World Health Organization
VHBC	Voluntary Home Based Care Providers

CHAPTER I

Background

According to the 2011 Global HIV/AIDS Response second report in 2010, worldwide there are about 34 million people living with HIV/AIDS and 2.7 are newly diagnosed HIV positive cases. From this group 1.9 million are found in Sub Saharan African countries. The report also stated that currently in 22 sub-Saharan African countries including Ethiopia the incidence of HIV infection declined from the approximated number which is 2.2 million in 2001 to 1.9 million in 2010. Despite its prevalence the number of people who die from HIV/AIDS related opportunistic infections declined from approximated number which is 2.2 million in 2005 to 1.8 million in 2010. This happened particularly in Sub Saharan African countries due to an introduction and increased accessibility of ART, and the existence of social support (1).

In Ethiopia, the first HIV/AIDS case was diagnosed in 1984, and after 1998 HIV/AIDS policy was developed. “In 2001, the National HIV/AIDS Prevention and Control Council declared that HIV was a national emergency, leading to various interventions particularly focusing on prevention and behavior modification”(2). According to the national single point estimate in 2007 there are about 1.2 million people live with HIV/AIDS and its prevalence estimated to be 2.4% (2.9 % female and 1.9 % male) (3).

ART was introduced in Ethiopia in 2003, and in 2005 the Ethiopian Government launched free access for ART in different health sectors to improve quality of life of PLWHA (2). Since the introduction of ART in Ethiopia, the numbers of people who have died due to HIV/AIDS related infections has reduced. This is shown in the 2007 report issued by the Ministry of Health demonstrating that the number of deaths due to HIV/AIDS was about 99,814 but in 2010 the number approximately reduced to 28,073(4).

AMREF Ethiopia is one of the international NGO working in different regions of the country with the aim of lasting health change in Africa. Strengthening home-based and palliative care for people living with HIV and chronic disease is one of the AMREF projects has been implemented in two sub cities of Addis Ababa called Gullele and Yeka sub City. The project has been providing care and support for about 5990 PLWA and chronically sick patients since July 2010. Currently this project provides care and support for about 818 people out of these people 659 of them are PLWHA (69 are < 18 years and 590 of them are > 18 years). From 590 of PLHIV 458 of them are on ART treatment. The beneficiaries of this project are supported by community home based care givers and the woreda health office to obtain the necessary medical, psychological, emotional and social support. Moreover, some of the beneficiaries engaged in income generating activities to bring sustainable change in their quality of life.

Significance of the Study

This study will be helpful in assessing the treatment adherence of HIV/AIDS patients in the project implementation area which is Yeka and Gullele Sub City. The result of this study will be helpful in assessing the situation of HIV/AIDS patients as well as the contribution of CBOs and FBOs in helping PLWA in adhering to their ART treatment. Moreover, the outcome of this study will contribute in developing another intervention program in the project implementation area.

Statement of the problem

In HIV care and treatment, adherence to ART is highly important. Achieving at least 95% adherence is vital for preventing viral resistance and treatment failure (5). This will be accomplished by implementing HIV/AIDS health network model. This model is very important in strengthening the health system in the provision of treatment, care and support for people living with HIV/AIDS. Involving available CBOs, FBOs, VHBC, associations, and NGOs to collaborate with the available health sectors is vital for the success of HIV/ AIDS care and support program. The collaborative work between health sectors and other responsible parties is vital and complementary on bringing successful result on improving quality of life of people living with HIV/AIDS (3). This concept is also stated in the Ethiopian 2005 ART guidelines that in order to obtain an effective outcome on ART adherence the involvement of community stake holders is very useful. Here the major community stakeholders are defined as "PLWHA, groups and associations of PLWHA, families and friends of PLWHA, NGOs, CBOs and FBOs that are providing prevention, care, treatment or support services, community leaders (such as religious and traditional leaders), community health workers, and traditional healers" (2). These groups are very important and resourceful section of the society for successful implementation of ART treatment, care and support.

There are various studies conducted concerning HIV/AIDS prevention, ART adherence, treatment, care and support among PLWHA. A study conducted by Pankhurst and Mariam (2004) described the importance of involving community based organizations like *Iddirs* on HIV/AIDS prevention and control program to bring successful result. This study focuses more on HIV/AIDS prevention and control instead of focusing their contribution on ART adherence among people infected and affected with HIV/AIDS (6). In addition to this a study conducted by Markos, Worku, and Davey (2008) focuses on assessing reasons that have an impact on ART adherence among HIV/AIDS patients,

but it does not give much attention on the role of CBOs, FBO on ART adherence. This study tries to assess the contribution of demographic, social, mental, and health condition of patients on non adherence of ART treatment among HIV/AIDS patients (7). Another study conducted in India focused on the contribution and importance of social factors like family relationships, from which the presence of trust and social support is vital to enhance ART treatment adherence (5). This study provides emphasis on family support and interpersonal relationship among family members instead of placing value on the contribution of CBOs and FBO on ART treatment adherence (5). Since most of studies do not provide emphasis on describing the adherence of PLWHA to ART treatment and the roles and contributions of CBOs and FBOs on ART adherence specifically in Yeka and Gullele sub city, this operational research will provide evidence on the role of community and faith-based organizations on ART treatment adherence as well as factors which have an effect on treatment adherence among PLWA who live in Yeka and Gullele Sub city.

Objective

General objective

- Assessing ART treatment adherence among PLHIV in Yeka and Gullele Sub City.

Specific Objectives

- To identify factors that affect treatment adherence among HIV/AIDS patients.
- To assess the role of FBOs and CBOs on ART adherence.
- To assess the experience of HIV/ AIDS patients in relation to their treatment adherence.

CHAPTER III

Methodology

Study Area

The focus areas of this study are going to be Yeka sub-city (woreda 5, 8, 9) and Gullele sub-city (woreda 5& 7) where Strengthening home based care project implemented since July 2010.

Study population

The participants for quantitative methods will be approached by recruiting them from caregivers contact list by using simple random sampling method and the participants for qualitative data collection was selected by using purposive sampling method.

For quantitative data gathering the participants was selected based on the following inclusion criteria:

- Whose age is 18 years and above ,
- Have been on ART treatment for more than three months
- Who were willing to participate in the study

For qualitative study the participants are selected based on the following inclusion criteria:

- Stake holders who have been working with the CHBC project and have enough knowledge about the beneficiaries.
- Have an experience of working with PLWHA in the study area
- Member of Home Based care givers who are working with AMREF
- Have willing to be tape recorded for in-depth interview

For focus group discussion the participants are selected using purposive sampling method using the following inclusion criteria:

- Has an experience of working with PLWHA.
- Group members who has similar experience.
- Member of CBOs and FBOs who are willing to participate in the study
- Members of CBOs and FBOs who have an experience of providing care and support for HIV/AIDS patients

- Have willing to be tape-recorded

Research design

This descriptive and exploratory operational research focused on the role of CBOs and FBOs on ART treatment adherence among HIV/AIDS patients. It was conducted by using concurrent mixed method approach. This approach was important to analyze the research problem from different directions or triangularly by concurrently collecting both qualitative and quantitative data (8). The quantitative approach was important to assess factors that contribute to ART adherence among HIV/AIDS patients and the qualitative approach was used to explain the experience of HIV/ AIDS patients and the concerned parities in relation to ART treatment adherence.

Sample size

This study was conducted among PLWHA who are served by CHBC project. The total numbers of PLWHA who were served by this project are around 590 whose age is 18 years and above.

$$n_o = (Z_{\alpha/2})^2 \frac{P(1-P)}{d^2}$$

Assumptions:

Desired precision (d) = 5%

Expected prevalence (p)= Since the contribution of FBO & CBOs on ART adherence is not known=50% (p=0.5)

Confidence level = 95%, which means α set at 0.05 and $Z_{\alpha/2}$ = 1.96 (value of Z at α 0.05 or critical value for normal distribution at 95% C.I.).

Hence, the calculated sample size is 384.

The study subjects were selected by using simple random sampling method.

For qualitative data gathering 2 members of CBOs, FBOs leaders, 2 members of woreda health office leaders, and 2 members of VHBC providers were included for in-depth interview.

Four focus group discussion 4 homogenous groups with a member of 8 participants were selected.

Data collection procedure

The qualitative and quantitative data was collected after giving one day training for data collectors. Tools pretest was conducted on February 15, 2012 and then final data was collected from February 18- February 25, 2013. Qualitative information will be collected by using in-depth interview and focus group discussion through interview guide, and quantitative data was collected by employing structured and semi structured interview questions.

Data analysis

The information obtained from both qualitative and quantitative date was be analyzed based on the type of the collected data. The information obtained from in-depth interview(IDI) and focus group discussion was transcribed from the audio tape into written form and its accuracy was checked by listening it repeatedly. The written information was translated from Amharic to English by frequently reviewing the translated information using dictionary to ensure accurate transcription. The transcription was arranged depending on the source of the information and the research questions. This information was thematically analyzed using open code soft ware. On the other hand, the information obtained from quantitative research was be analyzed by using descriptive and inferential statistics. It will begin by data entry and cleaning using EPI info version 6. Data analysis was performed using SPSS version 20. In addition, to identify the association between independent and dependent variables logistic regression and odds ratio was used. While analyzing the quantitative data considering the role of FBOs and CBOs on ART adherence is vital for bringing successful result in the provision of care and support for PLWHA. This study will identify various factors that have an effect on ART treatment adherence. Some of the contributing factors are Physical condition of the patient, social factors (social bond, interpersonal relationship, lack of trust, stigma and discrimination), Knowledge or having information about the importance of adhering to ART treatment, economic problem, and religious belief, lack of food, personal thought and misconception about the ART drug.

Ethical consideration

At the problem selection stage of the research, I identified an issue that benefited and not marginalized the individuals being studied (8). The participants will be provided with the necessary information about the study and they have the right to ask question, participate voluntarily or withdraw as they want. They will be informed that their participation in the study is voluntarily and their participation does not have any relation with the service they obtain from the CHBC project. In addition to this, the participants will be assured that the information they provide us will be confidential and pseudo names will be utilized while presenting the findings of the study.

CHAPTER IV

Finding of Qualitative Data

Back ground of the participants

Composition of the participants for in-depth interview

Name	**Name of the organization**	**position**	**Education**	**sex**
Participant 1	Hibret Meselal Idir	member	Diploma	Male
Participant 2	Yetebaberut wondemamachoch Meredaja Mehaber	member	12 complete	Male
Participant 3	Yeka	Voluntary Home Based Care Giver	Grade 10	Female
Participant 4	Gulelle	Voluntary Home Based Care Giver	12+2	Female
Participant 5	Gullele Woreda 5 Health Center	Health extension worker	Diploma	Female

Participant 6	Yeka Woreda 8 Health Center	Health extension worker	Diploma	Female

The above table shows participants of the In-depth interview who are Voluntary Home Based Care giver, Health professional who provide care and support for PLHIV, and Idir members. The above table shows that all of the participants are grade 10 and above and 4 of them are females.

Background of the participants for FGD

Representatives	No	Male	Female
idir	**14**	**10**	**4**
women association	**3**	**0**	**3**
youth association	**6**	**4**	**2**
Church			
Mosque	**1**	**0**	**1**
Association	**3**	**3**	**0**
total	**27**	**17**	**10**

The participants of FGD are 27 who are selected from Idir, women association, youth association, Mosque and Association that work on HIV/AIDS. The above table shows that from the total of the participants 17 of them are males and 10 of them are females.

Factors that affect treatment adherence among HIV/AIDS patients

The finding of the study indicated that in the past one month, 117(41.8%) of the participants missed their ART medication whereas, 160 (57.1%) of them were fully adherent. From the FGD and IDI findings major reasons that affect ART adherence are hopelessness, fear of stigma and discrimination, fear that others might see them when they take the ART drug, believing that using only holy water will cure them from their illness, anger and disputes with spouse, lack of food, substance and alcohol addiction. The participants of qualitative study also mentioned that those people who did not adhere to their ART treatment commit suicide, become critically ill and died. Following this problem CBO (Community Based Organization) and FBO (Faith Based Organization) members mentioned that they tried to teach the community to bring behavioral change on reducing stigma and discrimination and provide care and support for PLHIV.

FBOs and CBOs on ART adherence

From the qualitative findings, the contribution of *Idir* (traditional community based organization) leaders in relation to ART adherence is minimal but they focused more on prevention activities, provision support for OVC(Orphan and Vulnerable Children) and terminally ill patients. In addition to this some of the participants of FGD mentioned that the role of CBOs and FBOs reduced since phase out projects that work together with them in relation to HIV/AIDS. The finding of the FGD and IDI also describes that the participants of qualitative data who are member of CBO and FBO and VHBC givers stated that currently the focus of Idir and Religious leaders more on HIV/ AIDS prevention and reducing stigma and discrimination. The role played FBO leaders in relation to ART adherence become changed after giving different awareness creation training. Now a day's majority of religious leaders' advice people on the usage of ART together with holly water but still there are few religious leaders relate HIV/AIDS with evil spirit and advice PLHIV not to use ART together with holly water.

The finding of the qualitative data indicated that participants of the FGD and IDI mentioned that after they get training from AMREF on HIV and ART adherence they

bring change on awareness creation on HIV/ AIDS and reducing stigma and discrimination of PLHIV and their family members in the community. In relation to ART adherence VHBC givers play a paramount role on ART adherence by providing emotional and psychosocial support as well as provision of care and support.

> One of the VHBC giver said that *'I tell to my clients they are lucky to have ART drug freely because the former PLHIV did not get the treatment freely but now they get the treatment in every health facility freely. Thus, I initiate them to use this opportunity by adhering themselves with ART drug properly and keep their wellbeing"* (VHBC giver, Gullele).

The other VHBC givers also describe her experience in relation to ART adherence and Holly water:

> '*When people go to holy water treatment they stopped their ART drug and they become weak but currently there is improvement compared to previous time because there are religious leaders who aware the situation of patients they permitted to take the ART drug together with holly water in holly water centers'*(**VHBC giver w.8)**

Experience of HIV/ AIDS patients in relation to their treatment adherence

The experience of some patients who use ART treatment as described by Voluntary Home Based Care Providers, initially some of their clients were bedridden before they take their medication after they start taking their medication they became self-sufficient and involved in income generating activities. Many of the study participants stated that the presence of ART made them live longer and they should follow their medication properly in order to sustain their life. Many of the participants of the study participants indicated that initially they faced some health problem like blurred vision, etching of their skin, and insomnia in relation to their ART treatment but after they adapt their medication they become in a good health condition.

The finding of the study indicated that PLHIV use different mechanisms to remind and take their medication like using mobile alarm, news time of the radio and Television, & one of their family members reminds them their medication time.

One of the study participants mentioned on what mechanisms that she used in order adhere to her ART treatment:

> *'I use alarm of my watch; I took my medication and water where ever I go' (PLHIV, Yeka, Married)*

The other participants also indicated that on how her family member support her in her ART adherence

> *'I strictly remember my medication time and I took it properly, in addition to this specially my mother supports me by reminding the medication time (PLHIV,Yeka, Single)*

Conclusion and recommendation

The finding of the study indicated that role played by CBO and FBOs is more on awareness creation and prevention of HIV/AIDS where as their contribution in relation to ART adherence is minimal. It would be better for the government and NGOs to involve and support FBOs and CBOs to enhance their participation on ART adherence because they are the major stakeholders in the provision of care and support for HIV/AIDS patients.

References

1. WHO; UNAIDS; UNICEF. (2011). Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access- Progress Report 2011. Geneva, Switzerland.

2. Ministry of Health. (2005). Guideline for Implementation of Antiretroviral Therapy in Ethiopia. Addis Ababa, Ethiopia.

3. Ministry of Health; The Federal HIV/AIDS Prevention and Control Office. (2007). Single Point HIV Prevalence Estimate. Addis Ababa, Ethiopia.

4. Ministry of Health-HAPCO. (2007). Accelerated Access to HIV/AIDS Prevention, Care and Treatment in Ethiopia: Road Map 2007-2008/10. Addis Ababa, Ethiopia.

5. Ajithkumar, K., Neera, P., & Rajani, P. (2011). Relationship between social factors and treatment adherence: a study from south India. *Eastern Journal of Medicine* , 147-152.

6. Pankurst, A., & Mariam, D. (2000). *The Iddir in Ethiopia: Historical Development, Social Function, and Potential Role in HIV/AIDS Prevention and Control.* Retrieved 2011, from North African Studies: 10.1353/nas.2004.0018

7. Markos, E., Worku, A., & Davey, G. (2008). Adherence to ART in PLWHA at Yirgalem Hospital, South Ethiopia. *Ethiopian Journal of Health Development* , 174-179.

8. Creswell, J. (2003). *Research Design: Qualitative, Quantitative and Mixed Method Approaches.* Sage Publication.