EMPOWERMENT OF PEOPLE LIVING WITH HIV AND AIDS: THE CASE OF TESFA BILICHITA CHARITABLE SOCIETY TO PEOPLE LIVING WITH HIV

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTERS IN SOCIAL WORK (MSWP-001)

BY FANTAHUN MELESSE MERISSO

ENROLLMENT NO: ID1051106

NAME OF THE STUDENT CENTER: ST. MARY UNIVERSITY, ADDIS ABABA, ETHIOPIA

PROJECT SUPERVISOR: MR. EPHRAIM MEBRATE

SUBMITTED TO: INDIRA GANDHI NATIONAL OPEN UNIVERSITY, SCHOOL OF SOCIAL WORK

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Abstract

This paper has the objective to assess the contributions of People Living with HIV (PLHIV) associations in empowering PLHIV and reversing the impacts and prevalence of HIV and AIDS with particular emphasis on the case of Tesfa Bilichita Charitable Society to PLHIV ($TBCS^{+}$) in Assosa Woreda of BGRS. Qualitative method of in-depth interview, semi-structured interviews, focused group discussion (FGD), field observation and review of the pertinent documents were utilized as data gathering tools. Forty six participants were involved in the study.

The study report is divided in to 6 sections: The first chapter is an introductory part, the second chapter states the review of related literatures, the third chapter deals with the study design and the study area, the fourth chapter discusses analysis and interpretation of data, the fifth chapter states the main findings and the sixth chapter discusses conclusion and recommendations.

The findings of the study showed that the services provided by $TBCS^{+}$ have contributed in empowering the members and averting the spread of the HIV virus and the impacts of the epidemic. All of the services of $TBCS^{+}$ are relevant in empowering and reversing the impacts and prevalence of the epidemic, though the degree of the importance of the services varies from service to service. The provision of these services by $TBCS^{+}$ have contributed in improving the health conditions and the socio-economic status of the members, enhancing the social relationships of the members among their fellow members and the wider community, bringing attitudinal changes among the members to the virus and promote positive living with HIV. The organization is working towards the realization of its objectives and addressing the needs and priorities of the members, though the efforts need to further strengthen.

DECLARATION

I hereby declare that the dissertation titled "**EMPOWERMENT OF PEOPLE LIVING WITH HIV AND AIDS: THE CASE OF TESFA BILICHITA CHARITABLE SOCIETY TO PEOPLE LIVING WITH HIV"** submitted by me for the partial fulfillment of the MSW to Indira Gandhi National Open University, (IGNOU) New Delhi is my own original work and has not been submitted earlier, either to IGNOU or to any other institution for the fulfillment of the requirement for any other programme of study. I also declare that no chapter of this manuscript in whole or in part is lifted and incorporated in this report from any earlier work done by me or others.

Place: Assosa, Ethiopia

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CERTIFICATE

This is to certify that **Mr. Fantahun Melesse Merisso** student of MSW from **Indira Gandhi National Open University**, New Delhi was working under my supervision and guidance for his project work for the Course **MSW-001.**

His project Work entitled "**EMPOWERMENT OF PEOPLE LIVING WITH HIV AND AIDS: THE CASE OF TESFA BILICHITA CHARITABLE SOCIETY TO PEOPLE LIVING WITH HIV",** which he is submitting, is his genuine and original work.

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ACRONYMS

1. AIDS-Acquired Immuno Deficiency Syndrome
2. ART-antiretroviral therapy
3. BCC- Behavior Change Communication
4. BG HAPCO- Benishangul Gumuz HIV and AIDS Prevention and Control Office
5. BG-Benishangul Gumuz
6. BGDAN- Benishangul Gumuz Development Associations Network
7. BGRS- Benishangul Gumuz Regional State
8. CCRDA-Consortium Christian Rehabilitation and Development Associations
9. CSOs- Civil Society Organizations
10. CSWs- Commercial Sex Workers
11. DHS- Demographic and Health Survey
12. EBCA-Ethiopian Business Coalition on AIDS
13. EDHS- Ethiopian Demographic and Health Survey
14. ETB- Ethiopian Birr (currency)
15. FBOs- Faith Based Organizations
16. FDRE- Federal Democratic Republic of Ethiopian
17. FGD- Focus Group Discussion
18. FHAPCO- Federal HIV and AIDS Prevention and Control Office
19. FMOH- Federal Ministry of Health
20. GDP-Gross Domestic Product
21. GIPA -Greater Involvement of People with AIDS

22. GIPLHIV- Greater Involvement of Persons Living with HIV

23. HAPCO-HIV and AIDS Prevention and Control Office

24. HBC- Home Based Care

25. HCT-HIV Counseling and Testing

26. HIV- Human Immunodeficiency Virus

27. IEC- Information, Education and Communication

28. IGAs -Income Generation Activities

29. MARPs- Most at Risk Population

30. MDG- Millennium Development Goal

31. MOH-Ministry of Health

32. NBGP+ -Network of BG HIV Positives' Charitable Societies Consortium

33. NEP+- Network of Networks of HIV Positives in Ethiopia

34. NGOs- Non-Governmental Organizations

35. OIDs- Opportunistic Infectious Diseases

36. OSSA-Organization of Social Services for AIDS

37. OVC- Orphan and Vulnerable Children

38. PANE- Poverty Action Network in Ethiopia

39. PLHIV-People Living with HIV

40. PMTCT-Prevention of Mother- to- Child Transmission

41. RHAPCO-Regional HIV and AIDS Prevention and Control Office

42. SBM-Small Business Management

43. STIs- sexually Transmitted Infections

44. TBCS^{+}- Tesfa Bilichita Charitable Society to PLHIV

45. UNAIDS- Joint United Nations Program on HIV and AIDS

46. UNDP- United Nations Development Program

47. UNICEF- United Nations International Children Emergency Fund

48. US- The United States

49. USAID- United States Agency for International Development

50. USD- United States Dollar

51. VCT-Voluntary HIV Counseling and Testing

52. WHO- World Health Organization

Definition of Terms

1. Regions-are the states that together form the Ethiopian Federal Democratic Republic. Currently the FDRE consists of nine regional states and two City Administrations.
2. Zone-an administrative unit below Region and above Woredas. It consists of number of Woredas(Districts)
3. Woreda-an administrative unit below a zone and equivalent to a district and consists of a number of Kebeles.
4. Kebele- the lowest administrative unit in Ethiopia(village associations and urban neighbourhood associations)
5. Empowerment-to strengthen and improve the economic and social status as well as attitude, outlook and confidence of the PLHIV.

CHAPTER ONE

I. INTRODUCTION

1.1. **Background of the Study**

The emergence of HIV and AIDS epidemic is one of the biggest public health, psycho-social, economic challenges the world has ever seen in recent human history. In the last three decades HIV has spread rapidly and affected all sectors of society- young people and adults, men and women, and the rich and the poor (Country Progress Report on HIV/AIDS Response, 2012). HIV and AIDS create the most serious threats of global stability and progress through demolishing the human being particularly the productive and reproductive citizens who drive development. In Ethiopia, HIV/AIDS with poverty and drought is bringing a cripple effect on future prospects (Frehiwot, 2010).

The origin of this mysterious disease has puzzled every one ever since its recognition in early 1980s. Thereafter, HIV and AIDS have expanded in magnitudes and impacts and become one of the major challenges of health, life and development. According to USAID 2011 report cited in HIV and AIDS Mainstreaming Training Manual, May 2012, worldwide HIV and AIDS has been the cause of death for over 30 million people; about 34 million people live with the virus including 3.4 million children less than 15 years. In 2011 an estimated 2.5 million people were newly infected with HIV of which 330,000 were under the age of 15. Every day nearly 7,000 people contact HIV-nearly 300 every hour. In the same year 1.7 million people died of AIDS; 230,000 of them were under the age of 15.Since the beginning of the epidemic, more than 60 million people have contacted HIV and nearly 30 million have died of HIV-related causes(UNAIDS World AIDS Day Report 2012;UNAIDS Fact Sheet 2012 cited by Ermiyas,2013). As the MDG 2011 report, globally, nearly 23 per cent of all PLHIV are under the

age of 25, and young people (aged15 to 24) account for 41 per cent of new infections. Sub-Saharan Africa remains the most heavily affected region, accounting for 69 per cent of new HIV infections, 68 per cent of PLHIV and 72 per cent of AIDS deaths (UN 2011 MDG Report).

Ethiopia as the Sub-Saharan country and the second largest populous (with about 80 million people) state in Africa, it is among the countries most affected by epidemic. The existence of HIV in Ethiopia recognized in1980s with the first two AIDS cases reported in 1986(Lester FT and others 1988, cited in GAP Report on AIDS, 2012). Since then, the epidemic has rapidly spread throughout the country. With an estimated adult prevalence of 1.5%, Ethiopia has about 800,000 PLHIV including about 182, 200 children aged 0-14 years; and about 1 million AIDS orphans (Country Progress Report on HIV/AIDS Response 2012, the DHS 2011 data).

Benishangul Gumuz Regional State (BGRS) is one of the nine regional states in Ethiopia which is highly affected by HIV and AIDS. In BGRS the estimated adult prevalence rate is 1.2 %, and the annual death rate is 705 persons (Ethiopia Sub-National Estimates of June 2012).

The struggle against this devastative episode needs the concerted efforts of every actor at every level (2012 TBCS^{+} Annual Report).In the combat of HIV and AIDS, reversing its adverse effects and empowering the People Living with HIV (PLHIV), the PLHIV and their associations have valuable and significant contributions. But there is a gap in assessing, appreciating or proposing corrective recommendations concerning the contributions of the PLHIV associations in empowering PLHIV and reversing the impacts of HIV and AIDS. Taking all these facts into accounts and gaps in the wide arrays of literatures, this study aims to assess the contribution of PLHIV associations in empowering PLHIV and reversing the adverse impacts of HIV and AIDS with particular emphasis on Tesfa Bilichita Charitable Society to PLHIV (TBCS^{+}).

1.2. Statement of the problem

The impacts of the pandemic are felt in all areas of life. HIV and ADIS is not only a killer disease like other diseases known to human beings but also it becomes a source for the violation of human rights, and also it affects the development endeavor of a country. A paper produced by Ethiopian Business Coalition on AIDS (EBCA) in September 2009 on HIV/AIDS and Human Rights clearly reveals that how HIV and AIDS differ from other major killing diseases and antagonizes the values and principles of human rights, defame human dignity as follows"…What is the difference about HIV/AIDS? The impact is not only the physical health of individuals but also their social identity and condition; the stigma and discrimination surrounding HIV/AIDS can be as destructive as the disease itself; lack of recognition of human rights; and loss of dignity for people living with HIV or AIDS".

As HIV and AIDS is posing formidable challenges to all the development efforts and, responding effectively to the behavioral, psycho-social, cultural, and economic factors that make individuals and communities vulnerable to HIV infection and mitigating the associated crises of AIDS require organized and concerted efforts from all actors (FHAPCO Road Map, 2010). Unless strong action is taken, particularly in massively expanded and intensified prevention efforts, the pandemic will continue to threaten the delivery of sustainable social services and the attainment of the MDG (Frehiwot, 2010).

By understanding the values and importance of their involvement, the PLHIV associations are found playing their own roles in curbing the spread of the HIV and the impacts of HIV and AIDS. The PLHIV organizations are providing significant empowerment initiatives to the PLHIV and their families through education and VCT services; in care and support programs, the provision of ART and PMTCT services, and support to PLHIV and OVC (Country Progress

Report on HIV/AIDS Response, 2012). The meaningful involvement of PLHIV makes a powerful contribution to the HIV response. They draw on their experiences to reduce stigma and discrimination and increase the effectiveness and appropriateness of HIV programs. Moreover, PLHIV participation in designing policies and implementing programs has been instrumental for prioritizing, ensuring relevance and increasing the effectiveness of interventions. PLHIV participation in all aspects of HIV programs is a pre-requisite to creating programs that will best meet peoples' needs and mitigate the impact of the epidemic (TBCS^{+} Annual 2013 Plan).

Research papers and findings began to be produced in relation to the PLHIV Associations and Networks in particular and the issues related with HIV and AIDS in general. The associations of PLHIV are providing social support and encouragement; hope and a safe haven for sharing of experiences, seeking refuge from discrimination, finding moral support and encouragement, as well as obtaining financial assistance, particularly for the poorest who are the main participants of such associations(Alula Pankhurst and others, 2008). Anania(2000),provides a background to the establishment and development of PLHIV associations in Addis Ababa, the MA theses of Sebsib(2002) and Mekete(2005) provide evidence on growing supports of such associations in Bahir Dar and Nazreth respectively(cited in Alula et.al 2008). Getnet (2008) in his MA thesis tried to assess "the knowledge, attitude and practices of rural women in relation to HIV and AIDS with particular emphasis on Wad- Eyesus Woreda of Amhara Region". Frehiwot (2010) assesses the "role of education sector in preventing and mitigating the impact of HIV/AIDS on development with particular emphasis in Ethiopia". Ermias (2013) studied the "provision of transaction-prevention and care services for Most at Risk Population by Integrated Services for Prevention and Support Organization and Pro Pride".

However, this researcher believes that the studies on contributions of the associations of PLHIV in empowering the PLHIV and reversing the impacts of HIV and AIDS are inadequate and that of BGRS is absent. Thus, this paper tried to assess how far the associations of PLHIV contribute in empowering PLHIV and reversing the impacts and prevalence the epidemic with particular emphasis on Tesfa Bilichita Charitable Society to PLHIV ($TBCS^{+)}$ of Assosa District of BGRS.

1.3. OBJECTIVES OF THE STUDY

The general objective of this study was to assess the contribution of $TBCS^{+}$ in empowering PLHIV and reversing the impacts and prevalence of HIV and AIDS.

This study specifically intends to:-

1. Assess the contributions of the services of $TBCS^{+}$ in empowering the PLHIV and reversing the impacts and prevalence of HIV and AIDS.

2. Assess the alignment of the interventions of $TBCS^{+}$ with the HIV and AIDS policies.

3. Review how far $TBCS^{+}$ meets its objectives.

1.4. Significance of the Study

A number of studies have been conducted on HIV and AIDS related topics and issues. These studies mainly focus on HIV and AIDS related discrimination and stigma; impacts of HIV and AIDS; HIV and AIDS counseling and testing; etc. Nevertheless, the assessment of the contribution of PLHIV Associations in empowering PLHIV and reversing the effects of HIV and AIDS is overlooked. So, there is a need to conduct practical research that shows the contribution of PLHIV associations. The researcher believes this study helps to reveal the services that have been provided by the associations of PLHIV to their members and their effects in empowering

the beneficiaries and reversing the impacts of HIV and AIDS; to show how far association's intervention align with the HIV and AIDS policies and strategies with particular emphasis of $TBCS^{+}$.

It may also serve other associations of PLHIV to evaluate their interventions in light of the findings and recommendations of this paper. In addition, it will pave the way for other researchers to further investigate the contributions of the associations of PLHIV in empowering PLHIV and reversing the impacts of HIV and AIDS. Moreover, this study may initiate the concerned bodies to give due attention to PLHIV associations and support their cases and efforts.

1.5. Ethical consideration

Informed consent is the major ethical issue in conducting Social Work Research. In this regard, the informed verbal consent was obtained from each of the study subject. Each participant of the study was informed the objective of the study and his/her right to voluntarily participate in the interview or not. They freely participated in the study by understanding its objective. Each participant was communicated that his/her answer would remain anonymous, confidential and only to be used for the study purpose.

CHAPTER TWO

II. REVIEW OF RELATED LITUTRATUE

This section discusses comprehensive review of different topics related to the issue under consideration. Literatures related to the prevalence of HIV and AIDS (global, African, Ethiopian and BGRS context), the impacts of HIV and AIDS (economic, psycho-social, and health), government response to HIV and AIDS in Ethiopia and the contribution of PLHIV associations.

2.1. HIV and AIDS Epidemic: Global Context

The emergence of HIV and AIDS epidemic is one of the biggest public health, psycho-social, and economic challenges the world has ever seen in recent human history. In the last three decades HIV has spread rapidly and affected all sectors and groups of the society- young people and adults, men and women, the rich and the poor (Country Progress Report on HIV/AIDS Response, 2012). No class, country, race, gender, or religion was spared from AIDS. Only the elderly who had stopped having sex and children aged six to fourteen normally escaped infection (Deborah et al, 2006:27). HIV and AIDS create the most serious threats of global stability and progress through demolishing the human being particularly the productive and reproductive citizens who drive development (Frehiwot, 2010). HIV and AIDS is the gravest health, psycho-social and economic development challenge to prospects and global security of the world at the moment (Beniam, 2013:8).

The origin of this mysterious disease has puzzled every one ever since its recognition in early 1980s. In 1982 AIDS was first detected in New York and San Francisco among the gays, since then the pandemic spread all over the world rapidly. According to Susan Hunter, a medical anthropologist, "HIV/AIDS is fast becoming the worst human disaster the world has even

known. Even if the cure is found tomorrow, the toll of death and suffering by 2010 will far exceed any other recorded human catastrophe, any other previous epidemic, natural disaster, war, or incident of genocidal violence" (Deborah, et al, 2006:22). HIV and AIDS is the worst of all infectious diseases to face the world since the bubonic plague of the year 1347(Thomas, 2010:3; in Beniam, 2013:8).

Worldwide the pandemic has been the cause of death for over 30 million people (FHPCO: HIV and AIDS Mainstreaming Training Manual, 2012: 8). Globally, in 2012 there are an estimated 35.3 million PLHIV, 1.6 million AIDS deaths, increase in receiving ART, increased ART coverage to pregnant PLHIV women to 62 %, 2.3 million new infections which is showing a 33% decline in the number of new infections from the estimated 3.4 million in 2005, decrease in number of children newly infected with HIV by 35 % from 2009, there was an annual decrease in number of new HIV infections among adults and adolescents by 50% or more in 26 countries between 2001 and 2012 although other countries could not reduce sexual HIV transmission by half, recent surveys in many Sub-Saharan countries have revealed decreases in condom use and/or an increase in the number of sexual partners (UNAIDS, 2013:4-6).

2.2 HIV and AID: the African Context

The African continent in general and Sub-Saharan Africa in particular is worse and heavily affected by HIV and AIDS than any other region of the world. Although the burden varies from region to region and countries to countries, the Sub- Saharan Africa remains most affected, with nearly 1 in every 20 adults (4.9%) living with HIV and accounting for 69% of the PLHIV worldwide.. The number of people dying of AIDS related causes in Sub Saharan Africa declined

by 32% from 2005 to 2011, although the region still accounted for 70% of all the people dying from AIDS in 2011(Lemlem, 2013:7- 8).

The most devastative effects of HIV and AIDS epidemic have been concentrated in Sub-Saharan Africa (Brown 1996, in Elizabeth, 2008:5). In 2011 PLHIV in the region estimated to be 22.9 million - around two thirds of the global total (UNAIDS, 2011). The continent with just 10% of the world population was the home to over 75% of the World's PLHIV and about 150 million individuals were believed to be either directly or indirectly affected by the epidemic (IPAA 1999). Sub Saharan Africa is not only the region worst affected by the disease but also it is concomitantly the region with the lowest access to health care and social and economic safety nets (Price 2002; in Elizabeth, 2008: 5). Famines, the ancient killers in Africa, are now caused not only by drought and war but also because there are not enough healthy farmers to tend the fields (Deborah, et al, 2006).

Even in Africa the prevalence and effect of HIV is not similar all over the continent. The east, central and southern parts of Africa are worst affected (Oppong 1998), despite considerable variations in countries (UNAIDS, 2002). The first 6 highly affected courtiers (Botswana, Zimbabwe, Namibia, Zambia, Swaziland and Kenya) are found in these regions (the Economist 1998). Both HIV prevalence rates and the numbers of people dying from AIDS vary greatly between sub Saharan African countries: in Somalia and Senegal the HIV prevalence is under 1% of the adult population, in Namibia, Zambia, and Zimbabwe around 10-15%, in South Africa 17.8% in Botswana (24.8%), Lesotho (23.6%) and Swaziland (25.9%), in Cameroon 5.3%, in Gabon 5.2%, in Nigeria 3.6%.(UNAIDS, 2010). Adult HIV prevalence in East Africa exceeds 5% in Uganda, Kenya and Tanzania (UNAIDS 2008). From the countries of these regions, the southern region is the leading. In Swaziland, Botswana, Namibia, South Africa and Lesotho that

approximately 30% of the pregnant women are HIV positive. In Swaziland, 43 percent of all pregnant women attending prenatal clinics carry HIV along with their child, more than a tenfold increase over the 4 percent twelve years ago (UNAIDS, 2006:18).

AIDS is clearly the cruelest pandemic Sub Saharan Africa has even known; over 12.3 million children have been orphaned by the disease, 20 million lives have been lost, and 25million people are infected with the virus. The number of orphans will increase in the next decade as HIV positive parents become ill and die of AIDs (Madavo 2004 in H.M.N. Kodero, Elizabeth et al, 2008:77). According to the UNAIDS report, Nigeria, Ethiopia and Kenya are the first three largest countries in number of AIDS orphans (Elizabeth et al 2008:77).

"The future is grim for many African youth. Nine in ten children (under 15 years old) who are infected with HIV live in Sub-Sahara Africa" (UNAIDS, 2006:15). Today, the new generations in some of African states like in South Africa, Botswana, Swaziland, Namibia, Mozambique, Zambia and Lesotho "have only a one in two chance of ever reaching their life goals. The rest will die of AIDS first" (Deborah, et al, 2006). "Millions of children orphaned by AIDS in Sub-Saharan Africa are groping for a brighter future and are in dire need of intervention. Left without intervention, such children live in volatile and threatening world. They are the "prime target of HIV infection…Emotionally vulnerable and economically disadvantageous, such children are forced to live on streets and are easily drawn into selling sexual favors" (UNICEF, 1990: 17: quoted in Elizabeth, et al, 2008: 78).

HIV and AIDS have brought significant social, economic and political changes in African. The economic impact of HIV and AIDS is noticed in slower economic growth, a distortion in spending, increased dependency on international assistance and changing demographic structure

of the population. The social impact of the epidemic is most evident in the continent's orphan crisis- AIDS orphaned approximately 12 million children in Sub Saharan Africa (Inter Agency Proceeding Report on Coordination and Harmonization of HIV/AIDS, Tuberculosis and Malaria, (ATM) Strategies, 2006:20).

Some of key areas on which the HIV and AIDS impacts highly manifested are:

1. **Life expectancy**: The average life expectancy in sub-Sahara is now 54.4 years and in some of the most heavily affected countries the life expectancy is dwindled below 49 years (UNDP, 2011). In 26 African nations with the highest HIV and AIDS prevalence, average life expectancy is 48.3 years, 6.5 less than it would be without the disease (UNAIDs, 2007; in Tewodros, 2011:12)

2. **Household**: HIV and AIDS have shackled the very aspects of the households of the PLHIV, especially when families lose their income earners.
3. **Healthcare:** As the epidemic develops, the demand for care of AIDS patients rises, as does the number of health care workers affected.
4. **Schools and education**: Schools and education sector are also heavily affected by AIDS.
5. **Productivity**: The epidemic has dramatically affected labor force, which in turn slows down socio-economic activity progress. The vast majority of PLHIV in Africa are the main working forces (ages of 15 to 49). Employers, schools, factories and hospitals have to train other staff to replace those at the workplace that become too ill to work.
6. **Economic growth and development**: HIV and AIDS have already significantly affected Africa's economic development, and in turn, have affected Africa's ability to cope with the epidemic (http://www.avert.org/aids-impact-africa.htm).

2.3. HIV and AIDS: the Ethiopian Context

In Ethiopia the virus first detected in 1984 and the first two AIDS cases were reported in 1986. According to the FHAPCO(Federal HIV and AIDS Protection and Control Office): HIV and AIDS Mainstreaming Training Manual, 2012: 9, in Ethiopia the HIV prevalence rate at average is 1.5 %(male 1.0% and female 1.9%); the urban prevalence rate is 4.2% and the rural 0.6%; among PLHA 289,000 adults and 82,000 children are estimated to be eligible to ART; the number of AIDS orphans is estimated to be 952,700; prevalence rates are highest in Gambela Regional State (6.5%) and lowest in Southern Nations, Nationalities and Peoples State(SNNPS) 0.9%. According to the USAID, PACT and UNICEF Document 2011-2016 Program, cited by Lemlem 2013: 3, there are 5.5 million orphans-15% of the total child population, 16% of them orphaned due to AIDS and there are 77,000 children headed households.

With over 1.2 million PLHIV, Ethiopia carries one of the largest HIV disease burden in the world and there is a marked heterogeneity across difference sub groups of the population, residence and region (FHAPCO: HIV Prevention Package, 2011:2).Wider differences observed among regions both urban-rural. Urban HIV prevalence ranged from 2.3% in Somali region to 11% in Afar, with substantial variation between the largest Ethiopian regions as well (Oromia 6.1%; SNNPS 6.9%; Amhara 9.8%; and Tigray 10.9%); while the rural HIV prevalence ranged from 0.4% in Somali region to 1.4% in Amhara region(Ibid).

There are various factors that precipitate the transmission of HIV in Ethiopia: the presence of sexually transmitted infections, gender inequality, multiple sexual partners, prostitution, alcohol, unsafe bleed transfusion and transmission from infected mother to fetus/child during pregnancy and breast- feeding (MOH, 2010: 22 cited in Beniam, 2013: 10). In Ethiopia, HIV and AIDS

with poverty and drought is bringing a cripple effect on future prospects (Frehiwot, 2010). The effects of HIV and AIDS are complex and far reaching. According to the sixth national report of the Ministry of Health (MOH,2006) the impacts of the epidemic are revealed on the national economy, health care, population growth, average life expectancy and teaching- learning process. HIV and AIDS pandemic also threaten food security, productivity, human resources and development in Ethiopia. The scale and the magnitude of the problem caused by this pandemic clearly demonstrate that the battle against it cannot be won easily. The country finds her in an extra-ordinary situation which requires extra ordinary measures, capacities and commitments (Tewodros, 2011: 14).

2.4 . HIV and AIDS: the BGRS context

Benishangul Gumuz Regional State (BGRS) is one of the nine regional states in Ethiopia. BGRS is one of the highly affected regions by HIV and AIDS. According to the Ethiopian Sub-National Estimates of June 2012, in BGRS the estimated adult prevalence rate was 1.2 %,(male 0.8% and female 1.5%), of which the prevalence rate in urban areas was 3.0 %(2.0% for male and 3.9 for female) and in the rural areas it was 0.6 %(0.4% for male and 0.8% for female). According to the same source, there were 8,456(3,335 male and 5,121 female) PLHIV; 230(102 male and 128 female) new infection; the adult HIV incidence was 0.03; 542(232 male and 310 female) annual death; 4,417(1,775 male and 2,643 female) persons need ART; and563 pregnant women with the virus . In 2012, in the region, from the children population (0-14 years old) 2,102(1,053male and1,044 female) were HIV positive; 141(71 male and 70 female) children lost their lives because of AIDS; 97(49 male and 48 female) children were newly infected; 936(471 male 465 female) children were in need of ART. In 2012 there were 61,661(from 0-17 years old) orphans

of which 12,743(20.7%) were AIDS orphans. So, in BGRS the number of AIDS orphan is greater than the national average which is 16% (Lemlem, 2013:3).

According to the 2011 EDHS estimate, BGRS is one of the regions which made great stride in reducing the prevalence of the epidemic. The region stood fourth in reducing the prevalence of the virus to 1.3%, next to SNNPS (0.9%), Oromia(1.0%) and Ethiopian Somali(1.1%) regions. The region has given due attention to curb the spread of the epidemic and developed the five year HIV and AIDS Strategic and Management Plan (Regional HAPCO, June 2014, Annual Performance Report). According to, the Regional HAPCO 2006 Ethiopian Calendar (2013/2014 G.C) Annual Performance Report, within nine months, in the region 50,883(24,426 males and 26,457 females) served with the VCT services of which 424 persons found HIV Positive (185 or 0.75% males and 239 or 0.9% females). In the same time 8,809 pregnant women got VCT services of which 78(0.9%) found HIV positive. Since the inception of the free-ART services, 7,488 PLHIV registered for the service, 4,292 became eligible and 3,117(73%) continuing receiving the ART (Ibid).

2.5.The Impacts of HIV and AIDS

The epidemic has multiple socio- economic dimensions and implications since it affects adults in their most reproductive life (Guerny 1999; in Elizabeth, 2008:5). The effects of HIV and AIDS are widely felt, not only in the health sector but also in education, industry, agriculture, transport, human resources and the economy in general (AFRICA , 2012 Statistics for sub-Saharan Africa).

According to the FHAPCO, 2012:10-11, the impacts of HIV and AIDS are categorized as individual and family, community, organization, and country level impacts. At individual and

family level the epidemic affects quality of life; creates a significant loss of income due to increasing medical cost; and changes the households structures (with more female, child and elderly- headed households, the dissolution of households, women and girls tend to provide most of the care for sick individuals, changes in extended family system, and the loss of access to support services as a result of stigma and discrimination) while at community level it increases orphaned children, changes social values, increases social burdens, and influences social structure and functioning. At organization level, it creates absenteeism, loss of productivity, training replacements; increases benefits of payments, employees turnover, medical costs, and disrupts production and services whereas at country level it increases health costs, social burdens such as orphanage, and dependency ratio; demographic change; decreases life expectancy, retards development and productivity as a result of loss of workforces and increases mortality and morbidity.

2.5.1. The Economic Impacts of HIV and AIDS

The HIV and AIDS pandemic have clear and visible economic effects. The emergence of HIV and AIDS challenge economic growth by reducing the availability of human capital (Bell, 2003). Its economic effects manifest in various ways including PLHIV fail to work, require significant medical care which in turn cause a collapse of the economies and societies; it has left behind many orphans cared for by elderly grandparents, it roses mortality, reduces labor force, especially reduction of experienced, skillful and knowledgeable workers which result in reduction of productivity, increases in workers' time off to look after sick family members or for sick leave will reduce their work time and consequently lower productivity. The elongated time and resource depleting caring and mortality will also weaken the mechanisms that generate

human capital and investment in people, through loss of income and the death of parents. By destroying the productive generation the endemic greatly weakens the taxable population and in turn affects GDP, redirects the resource for HIV and reduce public expenditure for social services and bring pressure on the state's finances and slower growth of the economy (Greener R, 2002). By killing off mainly young adults, AIDS also seriously weakens the tax base and reduces the resources available to meet the demands for public expenditures including that aimed at accumulating human capital, like education and health services not related to AIDS(Bell et al, 2003:9)

The worst economic effect of HIV and AIDS is manifested at the house hold levels. "On the level of the household, AIDS results in both the loss of income and increased spending on healthcare by the household. The income effects of this lead to spending reduction as well as a substitution effect away from education and towards healthcare and funeral spending. For instance, a study in Cote d'Ivoire showed that households with an HIV and AIDS patient spent twice as much on medical expenses as other households" (Over M 1992).

The reports of the UNAIDS, WHO and the UNDP have also revealed a correlation between the decreasing life expectancies and the lowering of gross national product in many African countries with prevalence rates of 10% or more. HIV and AIDS reveal clear effect on macro-economic development. Studies focusing on Africa show that HIV and AIDS result with the annual loss of GDP to be around one percent (Bell et al, 2003:7).

2.5.2 The Psycho-Social Impacts of HIV and AIDS

AIDS has become the most dreaded disease of the time not for the fact that death is certain but it is also due to the stigma and discrimination that is attached to its very nature(Gracious, T

2009:5).“The truth of living with HIV is a constant remainder of the lack of acceptance and rejection found in our societies- living with HIV-demands silence and secrecy, because, in the best of cases, people perceive rejection and lack of acceptance even from health care providers, including psychologists”(Berhanu ,2013:6). PLHIVs are often shunned or abused by their family members, community members, employers, and even health professionals. The PLHIV need constant care, support, affection and acceptance by everybody and every entity. But the case is different and in most cases the family members of the PLHIV even shy away from such responsibilities (Ibid, 7).

Edwin Cameroon, a South African Judge, when he had known his HIV+ status, expressed his feeling by the following heartbreaking words, “stigma is perhaps the greatest dread of those who live with AIDS and HIV…stigma’s irrational force springs not only from the prejudiced, bigoted, fearful reactions others have to AIDS…it lies in the fears and self-Loathing, the self-undermining and ultimately self-destroying inner sense of self blame that all too many people with AIDS and HIV experience themselves” (Knight, 2008). Stigmatization and discrimination are the main barriers for a successful HIV-Prevention. “Stigmatization and Discrimination act as impediments to uptake of HIV testing, treatment and care and to adherence to treatment (UNAIDS, 2009, HIV-related stigmatization and discrimination).

Stigma and discrimination to PLHIV still continue in many countries. Discriminatory treatment of PLHIV remains common in multiple facets of life, including access to health care and become the major challenges to an effective HIV response in all parts of the world (UNAIDS, 2013: 7). The spread and impact of HIV and AIDS epidemic itself aggravated by the prevalence of socio-economic inequalities between men and women and the incidence make women and girls more victim and vulnerable to HIV and AIDS especially in the medium and low income countries.

"The AIDS epidemic is aggravated by social and economic inequalities between men and women. Women and girls commonly face discrimination in terms of access to education, employment, credit, health care, land and inheritance. These factors can all put women in a position where they are particularly vulnerable to HIV infection. In sub-Saharan Africa, around 59% of those living with HIV are female" (UNAIDS, 2011, World AIDS Day, 2011). The situation was worse for the young women and in Africa with women making up 70% of young people in the region living with HIV" (UNAIDS, 2011,).

Per the national mid-term reviews 62% of countries in Eastern and Southern Africa and 50% of countries in Asia and the Pacific report that they are not on track to eliminate stigma and discrimination (UNAIDS, 2013:90). Although undeniable achievement have been scored in relaxing and repealing restrictive and discriminatory laws, the discrimination and imposing restrictions on free movement, stay and reside of PLHIV still persist in number of countries. Many countries have abandoned restrictions on the entry, stay and residence of PLHIV and the overall international trend is towards the repeal of such discriminatory laws. For example, from 2000 to mid-2013, from the 96 countries, territories and areas with HIV-related travel restrictions 50 %(43 of them) rebuffed the restrictions. "Since 2010, 10 countries, territories or areas have eliminated restrictions on entry, stay and residence for PLHIV". But, eliminating the remaining HIV-related restrictions will require intensified action to remove such counterproductive and discriminatory laws from the remaining 43 countries (UNAIDS, 2013:92-93).

The other biggest social effects of AIDS are observed with the orphan crisis. "The AIDS pandemic is distressing because by killing both parents, it destroys the family, which is the most important institutions in the children's lives. This scourge dismantles an intense and irreplaceable bond between parents and children, a bond that is crucial for normal emotional,

social, and mental development of in human beings"(Levine et al 1996). AIDS leaves as its legacy a generation of orphans traumatized by multiple losses, isolation, stigma and grief. They are experiencing higher levels of anxiety and emotional disturbances because of their worries about the future and their living conditions after their parents die of AIDS. They lack the proper care and supervision they need at their crucial period. They look to society to provide them with care and support (NASCP, 1996, quoted in Elizabeth et al, 2008: 77).

2.5.3. The Health Impacts of HIV AIDS

HIV is a member of retroviruses (mutate randomly) and lentiviruses(long acting virus) (Gracious, T.,2009:5). HIV is a unique virus in human history in its rapid spread and extent in the depth of its impact since the first AIDS case was diagnosed in 1981, the world has struggled to come to grips with its extraordinary dimensions (UNAIDS and UNICEF, 1999 cited in Lemlem 2013:7).The extensive spread of HIV, the etiology agent that causes the AIDS, possibly began during the mid to late 1970s and early 1980s (Brown 1996, in Elizabeth, 2008:5,). People develop AIDS because HIV has damaged their natural defenses against disease. Since then, HIV and AIDS is recognized as an epidemic with devastating effects on morbidity, mortality, health care, and costs (Forsythe and Rau 1996, in Elizabeth, 2008:5).

It is said that HIV is unstable outside the body where it is quickly destroyed by heat, drying and detergents. Although HIV may be found in any body fluid, it needs sufficient amount of white blood cells in fresh blood, sexual fluids and breast milk to be transmitted to others. This means it is hard to get HIV from others except through sex or fresh blood –to –blood contact or from an HIV positive mother to her infant while pregnant, at birth, or after birth through breast feeding. The HIV virus is not easy to transmit, but the nature of the epidemic assures its spread. HIV may

take up to ten years between the time of infection and the onset of the clinically recognized AIDS, though the infected people can spread the virus to others and not even know they have it themselves (Deborah, et al, 2006:19).

The virus can spread within the body and transmit to others without manifesting any symptoms for some time; eventually the disease takes its toll on the body by damaging a person's immune system, paving the way for numerous diseases to move in. Although most of the signs of the diseases and infections related to HIV are common and similar for most of the PLHIV, sometimes in some other PLHIV the symptoms of AIDS related diseases and infections may be unusual and unique (Elizabeth, C; 2012)

"The earliest symptoms of HIV can resemble the flu and they generally clear up within a month or two. These symptoms may include fever, headache, fatigue, and swelling in the lymph nodes, particularly those in the neck and groin. But, not everyone who acquires HIV will experience these symptoms. Similarly, for several years, perhaps as long as a decade, a person with HIV may not have any symptoms at all, though the virus is still multiplying and transmitting to others" (ibid).

2.6. The Overview of Government Response to HIV and AIDS

HIV and AIDS is not a personal or a family problem but it is a challenge for each and every community, organization, country or a world. HIV and AIDS has created major development constraints in affecting communities, hence there is a need to give the epidemic prominence in development plans of the governments and agencies (Elizabeth, 2008:5) Thus HIV and AIDS requires a coordinated and concerted efforts of everybody or very entity. Cognizance of the diversified implications and effects of HIV and AIDS, the Ethiopian Government has been

taking and launching preventive and reversing measures immediately following the recognition of the appearance of HIV and AIDS in the country. The government attempted to rally support and mobilize resources from various sources-national and international partners through mainstreaming HIV prevention programs to public and private sectors, engaging Community Based Organizations, Faith Based Organizations in to the issue, and adopting policies and strategies (Lemlem, 2013, 13).

To give response to the new endemic Ethiopia has been taken measures after measures in developing and establishing number of systems, adopting policy documents, guidelines, five years strategic plans, mainstreaming the issue in to various sectors. To mention some:-

- The establishment of the National HIV/AIDS Task Force in 1985,
- The establishment of the department of National AIDS Control Program within Ministry of Health (MOH) in 1987,
- The launch of the HIV/AIDS surveillance activities in 1989,
- Design and implementation of two medium term prevention and control plans from 1987-1996
- The launch of a comprehensive HIV/AIDS policy in August 1998,
- The establishment of the National AIDS Prevention and Control Council under the chairmanship of the President of the FDRE in April 2000,
- The upgrading of the National HIV/AIDS Secretariat in to National HIV/AIDS Prevention and Control Office(HAPCO) in June 2002,
- The launch of fee-based ART initiative in 2003 and the free ART initiative in 2005. Now, 71,500 clients at 241 sites have been provided ART and the government has planned to further decentralize the ART services to existing health facilities (HAPCO, 2012);

- The development of two Five Years Strategic Plan and Management for Multi Sectoral Response SPM I (2004-2008) and SPM II(2010/11-2014/15),
- Ethiopia Joined the International Community in the Political Declaration on HIV/AIDS of the UN General Assembly issued in June 2006, which committed all countries to move towards universal access to HIV prevention, care and support by 2010. To ensure the quality HIV and AIDS services delivered at the community level, support the implementation and scale-up of the national response including the HIV and AIDS policy, the Strategic Framework on Prevention and Control of HIV and AIDS, the Supply and Use of ARV Drugs Policy, Ethiopia adopted and distributed various guidelines and standards(Lemlem, 2013: 13-14);
- The integration of services such as PMTCT and HIV counseling and testing (HCT) with family planning and maternal, newborn and child health services (lemlem 2013:14).

The recent reports reveal that with the concerted efforts, effective policies, strategies and guidelines, as well as commitments, there is hope of reducing the spread of HIV and reversing the impacts of the epidemic in Ethiopia.

Although there are remarkable achievements and improvements in the national response to HIV and AIDS particularly in the health sector interventions, there are still potential areas that need improvement including education sector, the workplace programs, and care and support for the OVC (Lemlem, 2013:13). The other key areas that need the cooperation of every and each actor includes low utilizations of some of the existing services(especially PMTCT), emergence of new at-risk population groups (young girls engaging in transactional sex, and low coverage of intervention for Most at Risk Population (MARPs), and ensuring quality of available services (FHAPCO,2012).

2.7 The Roles of PLHIV Associations and Civil Society Organizations

HIV and AIDS are posing formidable challenge to the development of all sectors. Therefore, responding effectively to the behavioral, psycho-social, cultural, and economic factors that make individuals and communities vulnerable to HIV infection and mitigating the associated crises of HIV and AIDS require organized and concerted efforts from all actors in the public sectors, the private sector, NGOs, FBOs, PLHIV and communities at large (FHAPCO Road Map, 2010).

The meaningful involvement of PLHIV and affected communities makes a powerful contribution to the HIV response by empowering PLHIV or affected by HIV to draw on their experiences to reduce stigma and discrimination and increase the effectiveness and appropriateness of HIV programs. Moreover, PLHIVs' participation in designing policies and implementing programs has been instrumental for prioritizing, ensuring relevance and increasing the effectiveness of interventions. PLHIV participation in all aspects of HIV programs is a pre-requisite to creating programs that will best meet peoples' needs and mitigate the impact of the epidemic (TBCS^{+} Annual 2013 Plan). Nowadays, the associations of PLHIV are a key driving force in the response to HIV and AIDS, giving a personal power to people living positively with the virus, and inspiring others to action (http://www.worldaidscampaign.org).

By recognizing the importance of the participation of PLHIV in general and through the formation of organized entities of PLHIV in particular that could coordinate and support the PLHIV and respond to the impacts of HIV and AIDS, numbers of PLHIV associations formed everywhere including our region. The PLHIV associations are scoring significant numbers of achievements. These associations are providing social support and encouragement; hope and a safe haven for sharing of experiences, seeking refuge from discrimination, finding moral support

and encouragement, as well as obtaining financial assistance, particularly for the poorest who are the main participants of such associations(Alula Pankhurst and others, 2008). Significant empowerment initiatives have been provided to the PLHIV and their families by PLHIV organizations through education and VCT services; in care and support programs, the provision of ART and PMTCT services, and support to PLHIV and OVC (Country Progress Report on HIV/AIDS Response, 2012).

Similarly, Report on National HIV Submit (2009) regarded that greater involvement of people living with HIV and AIDS (GIPA) as indispensable. In his speech at the National HIV Summit (2009), Mr. Tigabe Asres, Executive Director of the Network of Networks of HIV Positives in Ethiopia (NEP+), clearly shows the contribution of PLHIV and PLHIV Associations in combating the epidemic and reversing its effects as follows;

> *"Individual PLHIV and their associations have been at the forefront of the prevention effort particularly at the initial stage of the national response. This is the role they can continue to play if they are provided with the necessary support. Positive prevention is a strategy that has a major role to play in averting re-infection among PLHIV, between discordant couple and also reducing transmission to the general population. Thus, there is an urgent need to scale up the positive prevention activities initiated and involve the PLHIV community as a major stakeholder in the planning and delivery of the services both the health facility and community level."*

The Ethiopian National HIV and AIDS Policy encourage the PLHIV to participate in Information, Education and Communication (IEC). In countries like Uganda, Senegal and Zambia strong government leadership, communities and donors encouraged and supported PLHIV to participate in HIV/AIDS prevention. In Ethiopia, numbers of associations are increasingly being formed, some of them by PLHIV. Most organizations have developed programs that include HIV/AIDS education and counseling using testimony, music, drama and songs (Kenso HG and Zemene M, 2000: 19-20). The PLHIV associations train community

members, especially families of PLHIVs and neighbors, in home-based care in issues like skin care, wound management, protective measures and nutrition and develop HIV/AIDS education, counseling and social support programs and advocates that PLHIV come forward to be helped. The PLHIV associations have remarkable place in curbing the cultural barrier for HIV-infected women to attend public places and participate in their affairs. These associations helped to empower the PLHIV women through holding coffee ceremonies and arranging peer to peer education where women can talk freely (Alemu T 2002). The AIDS related patients prefer to be cared for by people sharing the same problem/ People Living with HIV (Admassu A, 2000). The PLHIV associations formed a support group and trained care givers of PLHIV. This longitudinal supports of PLHIV associations were able to enhance the care for PLHIV and their children (Ayalew S, 1991).

The need for initiatives and partnerships to be community-enabling in terms of overcoming crippling social stigma, discrimination and fear and promoting an environment in which information dissemination on HIV/AIDS, advocacy for behavioral change and VCT, as well as disclosure of HIV status without fear of retribution could effective with the involvement and support of the care and support organizations by PLHIV (Ethiopian Journal of Health Development - Vol 17, 2003).

Networks of PLHIV have been harnessing the leadership of PLHIV for number of years, global networks have been organizing numbers of international PLHIV conferences, Women PLHIV have made the needs and challenges visible of children, mothers and grandmothers living with and affected by HIV and Networks of PLHIV have been leaders in setting up The Global Fund against AIDS, TB and Malaria and have ensured the involvement of PLHIV is anchored in The Global fund mechanisms on global as well as national level(http://www.worldaidscampaign.org).

CHAPTER THREE

III. RESEARCH DESIGN AND METHOD

3.1. Research Design

The study used descriptive research design and qualitative research method. The researcher employed the descriptive research design as it helps to elicit information concerning the contribution of PLHIV associations in empowering their members and reversing the adverse impacts of HIV and AIDS. Descriptive research design helps to explain the existing conditions or relationships, prevailing practices, current beliefs, point of views or attitudes, processes that are going on and their effects and the developing trends. Qualitative research approach helps to study social phenomenon within its natural context. It also enables to have in-depth understanding of a few numbers of cases rather than a general understanding of many cases or people (Grinnel, 2001 cited in Etabezahu, 2013). Qualitative research is best suited for a topic, which is sensitive and emotional like HIV and AIDS that require empathy and understanding (Ermias, 2013.) According to Maxwell 2005, the qualitative method helps to understand the meaning of situations, event, experiences, and actions of participants.

3.2. Study Area

The study area of this project proposal is Assosa District of Benishangul Gumuz Regional State (BGRS), in Ethiopia. The BGRS is one of the nine regional states and two city administrations that constitute the Federal Democratic Republic of Ethiopia (FDRE). The BGRS is located in the western part of Ethiopia sharing borders with Amhara Regional state to the north and northeast, with Oromiya Regional State to the southeast and south, with South Sudan, and the Sudan to the west. BGRS is divided into 3 administrative zones as Assosa, Kamashi and Metekel; 20 Districts

(woredas) of which one is Special District, 1 city administration and 475 kebeles. Assosa is the capital city of the BGRS, Assosa Zone and Assosa Woreda and located 661 km far away from Addis Ababa in the west. The region has an estimated land area of 50,698.68 Sq. km.

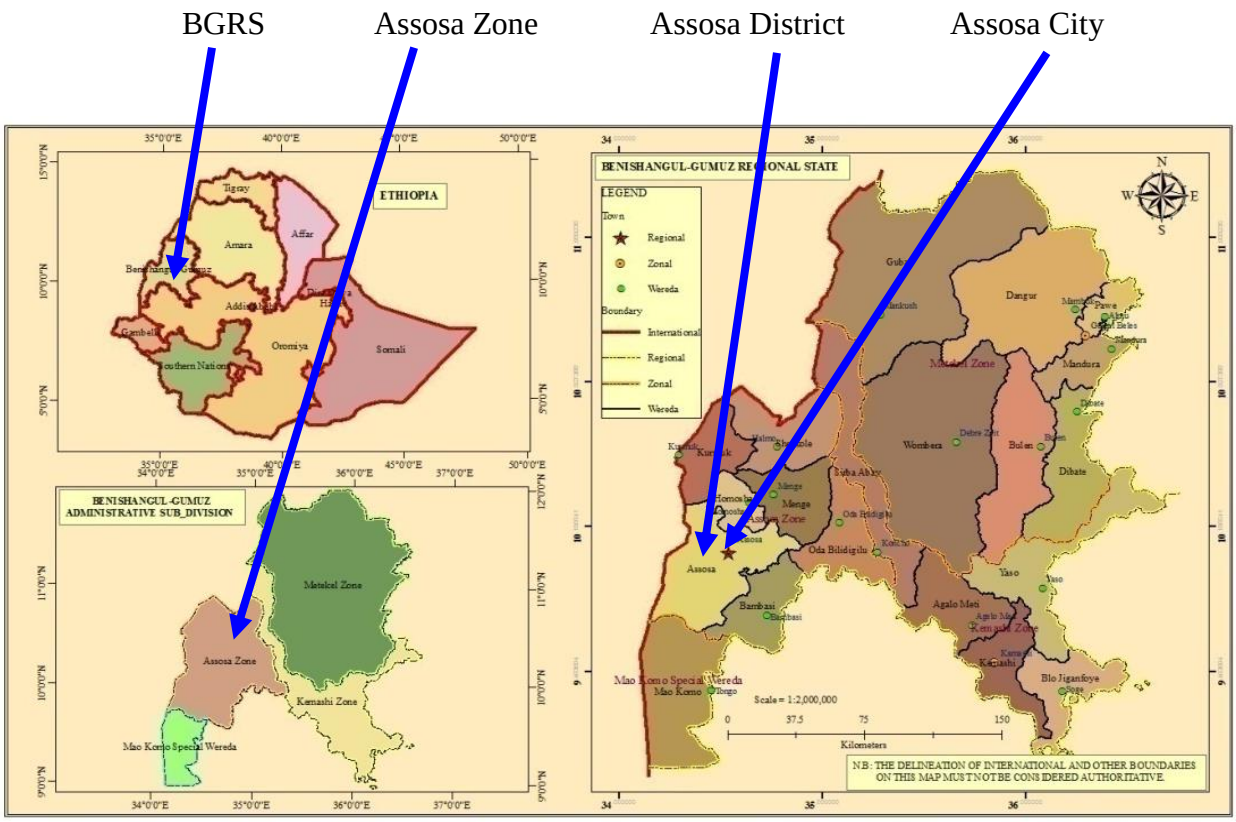

Fig.1.The Map of BGRS, Assosa Zone, Assosa Woreda and Assosa City

The mean annual temperature of BGRS is found between 23-25^{0}c in the low land and 10-15^{0}c in the high land. February to May is the hottest months while October to January is the coldest months. BGRS is a zone with great physiographic diversity. There are a great altitudinal differences between the highest and the lowest places. The lowest place is in the Blue Nile, which crosses the Ethio-Sudan border (443masl). Whereas, the highest peak in the region is Belaya plateau in Dangur woreda (2,857masl).

The BGRS is inhabited by five indigenous nations, nationalities and peoples, namely the Berta, Gumuz, Shinasha, Mao and Komo. In addition, other nations, nationalities and peoples including Amhara, Oromo, Agew, Tigrie, and Garage etc are also residing in the region (CSA, 2011). According to the 2012 projection, the overwhelming majority of the populations (83.4%) live in rural areas and the remaining 16.6% in urban centers. The population size of the region, as of July 2012 estimation was 982,004 (499,004/50.8% males and 483,000/49.2%) females.

The target district where, TBCS^{+} is operating is called Assosa. It is one of the 20 districts of BGRS. It is located in Assosa Zone. Assosa District has 74 rural kebeles and 4 urban kebeles of Assosa City. The rural areas cover the area of 2,917.67 sq. km and Assosa City has the area of14.58 sq.km. According to July 2012 estimation the Woreda had the total population of 133,757(68,052 males and 65,705 females) and it stands first in terms of population (it accounts 13.62 per cent the population of BGRS). From this population 37,365(19,232 males and 18,133 females) live in urban areas and 96,392(48,820 males and 47,572 females) in rural kebeles.

3.3. The profile of Tesfa Bilichita Charitable Society (TBCS^{+})

Tesfa Bilichita Charitable Society to PLHIV (TBCS^{+}) is a Charitable Society of Peoples Living with HIV. TBCS^{+} is a non-governmental, non-profit making, non-political, non-ethnic and non-religious based organization. Its operational area is Assosa District of the BGRS and its office is located in Assosa City. TBCS^{+} was established on 3 March 2002 with the aim to scale up and strengthen the overall efforts of PLHIV by mitigating the psychosocial and economic shocks of the members and family members.

It was registered on 14 January 2008, by the BGRS Bureau of Justice with the name of Tesfa Bilichita PLHIV Association. On 22 August 2011, the association registered as Tesfa Bilichita

Charitable Society to PLHIV ($TBCS^+$) by the Federal Charities and Societies Agency with registration number of *2425* per the Charities and Society proclamation (Procl. No 621/2009). Concerning its governance, the organization does have General Assembly (GA), Board of Directors (BDs) consisting of 7 members and the Secretariat.

$TBCS^+$ is working in the 74 rural Kebeles of Assosa Woreda and 4 kebeles of Assosa City.

Vision of $TBCS^+$

"Seeing a region where HIV and AIDS is not cause for psycho-social and economic evils on HIV positives and their families."

Mission of $TBCS^+$

"To mobilize financial, material and human resources and initiate and facilitate diverse income generating activities to get better livelihood of the charitable society members."

Objectives of $TBCS^+$

1. To reduce vulnerability and mitigate the impacts of HIV and AIDS on PLHIVs and their families
2. Reduce ART defaulter rate among ART attendant by 15 % at the end of 2015.
3. To improve the nutritional and income status of PLHIVs (mother support group) and OVCs
4. To strengthen the implementation capacity of the association members and its constituents
5. To mobilize required resource for the execution of planned activities of $TBCS^{+.}$

3.4 Study Population

The study population of this paper was the adult or the 455 members (188 or 42.32% males and 267 or 58.68% females) of $TBCS^+$. Currently the association has 455(188 males and 267

females) adult members and 79 (46 males and 33 females) children members. Totally the association consisted of 534(455 adult and 79 children, 234 males and 300 females') members. From these members, 35 (19 males and 16 females) were elders and 5(2 males and 3 females) were Person Living with Disability.

3.5 Sampling Technique/method

Non-probability sampling technique was used to identify participants of the study. Interview and Focus Group Discussion (FGD) were used as the main tool for data collection**.** The researcher employed the purposive sampling technique of non-probability sampling method. The purposive sampling technique was preferred due to its cost effectiveness and avoidance of time wastage. Purposive sampling technique is the most common sampling technique where participants of the study are selected according to pre-set criteria relevant to a particular research questions (Natasha et.al. 2005:6 in Ermias, 2013). To validate that informants meet the right criteria for the study, the researcher selected research participants based on age (18 years old and above), being member/beneficiaries of TBCS^{+}, consent to participate in the interview (for the beneficiaries); the criteria for board members were being voluntary to participate in the study; and for the staff members were being directly involved in the service provision for the clients and voluntary to participate. Generally, the respondents were selected on the basis of the purposes of the study and the inclusion criteria.

3.6 Sampling Size

The sample sizes/ the subjects of the study were 46 individuals including PLHIV beneficiaries, Board members and staff members. The samples include three groups of informants: 40 PLHIV members (beneficiaries) of TBCS+; 3 members of board of directors (the chairperson, the

secretary who is also the Executive Director of the organization, and one member); 3 project staff members (the project officer, the urban garden extension officer, and the finance officer). Ten members/ clients of the organization also participated in FGD. In addition, the researcher reviewed the organization's documents relevant to the study and visited the urban garden site.

3.7 Inclusion/Exclusion Criteria

The researcher included 46 respondents who satisfied the purpose and the inclusion criteria of the study. The inclusion criteria included age (18 and above), willingness and available to participate in the interviews, be member/ beneficiary of the organization, being members of the board of directors or a project staff of the organization. The beneficiaries those who are not PLHIV and under 18 were excluded.

3.8 Data Collection Tools and Procedures

Since social reality in general and social work research in particular are complex and multi-faceted activity, a single data collecting tool may not be adequate and suffice to gather the desired and relevant information. This study used various data collection tools so as to attain the objectives of the study. So, this study employed interview schedule, interview guide/protocol, focus group discussion (FGD), field observation and review of secondary data like reports, plans publications etc.

The main tool of data collection was interview schedule which was used to collect data from the 40 members/ service clients of TBCS^{+}. The interview questions comprised both closed and open ended questions. The interview schedule was pre-tested. Then the interview schedule was standardized, finalized and employed to the 40 members individually (individual interview). The

interview guide/ the semi structure interview were administered to the 3 boards of directors, and 3 staff members. The researcher conducted FGM with 10 selected beneficiaries. Moreover, the researcher performed field observation to the urban gardening site and documentary review.

Individual interview per participant (for the 40 PLHIV) guided by open ended and close ended questions was conducted with voluntary participant who fulfilled the inclusion criteria and consented to participate in the study. The interview was conducted in two -ways of communication form. In addition, the researcher also observed the feeling and emotion of the respondents.

Qualitatively the study was used various qualitative research methods such as beneficiaries' in-depth individual interviews through proving, semi-structured interviews with board of directors and staff members. Furthermore, the researcher reviewed and analyzed the available documents in light of the objectives of the research.

3.9. Data Analysis

The collected data were scrutinized, verified, edited and arranged serially. Following the completion of the individual in-depth interview through proving and semi-structured interviews and FGD, the researcher employed categorization and re-categorization of relevant themes in the study. By doing so, the researcher was used the thematic analysis of qualitative data. The relevant data gathered from the secondary sources or documents were analyzed and interpreted systematically.

3.10. Chapter Plan

This paper consisted of six chapters. These include:

1. The first chapter was an introductory part of the study.

2. The second chapter stated the review of related literatures.

3. The third chapter dealt with the study design, method and the area of the study.

4. The fourth chapter discussed analysis and interpretation of data.

5. The fifth chapter stated the main findings.

6. The sixth chapter discussed conclusion and recommendations.

The appendixes included the informed consent, the interview schedule, interview guide, FGD questions and references.

3.11. Report Writing

Every research is finalized by presenting its findings in the form of a report. The reporting of the results of a research study depends on purpose. So, since this study is a thesis for the partial fulfillment of the requirements for the Degree of Masters in Social Work, the results of the study would be submitted to Indira Gandhi National Open University School of Social Work in the form of report by following the conventional research reporting formats and in the sequential and logical manners. The present research report have three broad parts: the preliminary part, the main body and the end parts and each part would consist of sub- sections.

CHAPTER FOUR

IV. DATA ANALYSIS AND INTERPRETATION

This chapter presents the analysis and interpretation of the data collected from TBCS$^+$ clients, board and staff members on the contributions of the organization in empowering its members and reversing the impacts and prevalence of HIV and AIDS in Assosa District of BGRS. The data was gathered through structured in-depth interview (from the beneficiaries), semi-structured interview (from the board and staff members), FGD with sample beneficiaries, field observation and document review analyzed and presented qualitatively and quantitatively. This chapter is divided in to two sections: the first section on the socio-demographic profiles of the 40 beneficiaries and the second on the services provided by TBCS$^+$ and their contributions.

4.1 Socio-Demographic Profile of the Respondents

This sub-part states the socio-demographic profiles (age, sex, marital status, respondents position in the family, education status, occupation and monthly income levels of the respondents of the study(the 40 beneficiary participants of the study).

Table 1: Socio-economic Profile of the respondents

Item	Number and percentage				Remark
Age	18-30 (8/20%)	31-50(28/70%)	51-60(3/7.5%)	> 60(1/2.5%)	Total (40/100%)
Sex	Male (17/42.5%)	Female (23/57.5%)			Total (40/100%)
Marital Status	Married (22/55%)	Single (3/7.5%)	Widowed (4/100%)	Divorced (11/27.5%)	Total (40/100%)
Position in Family	Head (32/80%)	Wives (8/20%)	Others (0/0%)		Total (40/100%)
Education Status	Illiterate (5/12.5%)	Grades 1to 8 (27/67.5%)	Grades 9 to 12 (8/62.5%)	Certificate and above (0/0%)	Total (40/100%)
Occupation	Employees (19/47.5%)	Daily laborer and self employed (17/42.5%)	CSW (1/2.5%)	Jobless (3/7.5%)	Total (40/100%)
Monthly Income in Birr	< 500.00 (6/15%)	501.00 to 1000.00 (18/45%)	1001.00 to 1500.00 (9/22.5%)	>1500.00 (7/17.5%)	Total (40/100%)

In the study, totally 40 service clients or members of TBCS^{+} participated in the *in- depth individual interview*. As it is shown under *Table 1* above, the age distribution of the respondents vary from18 to 60 and above. From the total respondents, 8(20%) aged from18 to 30; 28 (70%) of the respondents aged from 31 to 50 years; 3(7.5%) from 51 to 60; and 1(2.5%) aged above 60.

So, the ages of the respondents varies from young generation to old age, though the great majority fall from 18 to 50(36 or 90%). The available data of TBCS^{+} also showed that the majority of the members and direct beneficiaries of TBCS^{+} were adults.

Regarding the age distribution of the respondents, as it is indicated *in Table 1 above*, out of the interviewees 23(57.5%) were females and 17 (42.5%) were males. This shows that the main service clients/beneficiaries of the organization were females. Even, the available data of organization shows that 276(58.7%) of the members and 595(67.4%) of the beneficiaries of TBCS^{+} were females (the organization totally has 455 adult members and 883 beneficiaries). Therefore, this finding showed that women are more vulnerable to the HIV and AIDS and victims of its socio-economic impacts than their male counter parts.

In relation to the marital status of the respondents, as *Table 1 above* shows 22(55%) of respondents were married, 11(27.5%) were divorced, 4(10%) were widowed, and the remaining 3(7.5%) were unmarried (single). Some of the respondents lost their former spouses due to HIV/AIDS related diseases. So, more than the one-thirds of the respondents was divorcees and widowers of HIV and AIDS. This figure indicates the vulnerabilities of widows and divorcees compared to other segment of the society.

As it is revealed *in the Table 1 above*, from the total of the 40 respondents 32(80%) were head of the households or bread owners, though that does not mean they all are men (which include

CSW, women headed households, widowed and divorced women etc. The remaining 8(20%) of the respondents were ladies of the houses (wives).

When we look the educational status of the subjects of the study, the majority of the respondent had not completed primary level education or grade 8 of which 5(12.5%) were illiterate who had not attended any form of formal education or had never been to school. Even the majority of the respondents 27(67.5%) ceased their formal education before completing primary level schooling or grade 8, though primary education is compulsory and free for all Ethiopians per the Educational Policy. Only 8(20%) of the respondents attended secondary school. But no respondent held certificate and above. Thus, this information reveals that the educational level of the majority of the respondents was very low. So, these individuals could not get better job opportunities to lead better and sustained lives.

Concerning the occupations of the interviewees, as explained *in Table 1 above*, they had been involved in number of jobs. Out of the total 40 participants, 19(47.5%) were employed in government offices, in private firms, and Civil Society Organizations but in low status and low earning jobs like cleaner, security guard, messenger etc; 17 (42.5%) of interviewees involved in daily labor and construction works or ran their own petty and micro enterprises by using the startup capital and trainings they had provided by TBCS^{+}; 3(7.5%) of the interviewees had no formal/paid works("were jobless")and lived as ladies of the houses; and the remaining 1(2.5%) was a Commercial Sex Worker (CSW).

With regards to the income of the respondents as depicted *under socio-demographics Table* above, the majority of the informants 24(60%) earned a monthly income, less than ETB 1,000.00 or less than USD50.00 per month, 9(22.5%) respondents got ETB 1,000.00 to 1,500.00 and only

7(17.5%) of the respondents (mainly those who are the construction workers and the CSW) received more that ETB 1,500.00 or more than USD 75.00 per month. From this data, one can judge that the majority of the respondents had living under poor conditions with low income.

4. 2. The Services of TBCS^{+} and Their Contributions in Reversing the Impacts and Prevalence of HIV and AIDS

4.2.1 Services Provided by TBCS^{+}

Any organization whether it is founded by an individual or group of people or government, the entity came in to being to realize certain objectives and is expected to carry out some activities, though the numbers, types, purposes, etc of the objectives and activities vary from entity to entity. Similarly, TBCS^{+} was established in March 2002 by five PLHIV reduce the impacts and the spread of HIV and AIDS. The organization aims to achieve its objectives by targeting PLHIV through the execution of various activities or provisions of number of services to PLHIV.

According to the organization's documents and the summarization of the Project Officer, the major services of the organization are grouped into the following 8 sub-services. These are:-

1. Home Based Care/HBC services**;** these services include:-
    - Family planning,
    - Hygiene and sanitation,
    - ART adherence, counseling and treatment education,
    - Referral linkage to health centers, hospitals and religious institutions,
    - Imparting information and messages about HBC services to their families,
    - Advice, psycho-social support,

- Awareness raising and health related education, and
- Palliative care, etc

2. Provision of emergency care and transportation cost to the sick PLHIV;
3. Provisions of funeral related services/ covering funeral costs like provision of coffin;
4. Provision of non-medical kits (blankets& bed sheet);
5. Nutritional support to chronically ill and bed- ridden PLHIV (plump nut);
6. Provision of pocket money and medical-kits (gloves, bandages, anti-septic drugs, savlone etc) to HBC service providers (each volunteer provided with ETB 250.00 per month).
7. Income Generating activities; the IGAs include:-
    - Small Business Management skills training,
    - Vocational training like vehicle driving, construction, female beauty salon, swinging, poultry farming, sheep & goat rearing, etc based on the interest of beneficiaries,
    - Provision of startup capital after the trainings/ in group or individually
8. Representation and rights protection of members.

Table 2: The Main Services Provided by TBCS^{+}

Name of Services provided by TBCS^{+}	Frequencies	Percentage (%)
1.Home Based Care services	40	100
2. Provision of emergency care & transportation cost	21	52.5
3.Provisions of funeral related costs	0	0
4. Provision of Non-medical kits	40	100
5. Nutritional support	18	45
6. Provision of pocket money and medical-kits	15	37.5
7. IGAs and capacity development trainings	40	100
8.Members representation and rights protection	40	100

According to the available data of TBCS+ and the responses of the interviewees, from the 8 main services of the organization 4 of them- HBC services, Non Medical Kits, IGAs and capacity development trainings, representations and rights protection of members' had been provided to all members. So, as it is depicted under *Table* 2 above, all of the respondents received these four services. Whereas, from the 40 respondents only 21(52.5%) received the services for emergency care and transport; 18(45%) provided with nutritional support; and 15(37.5%) serviced with the scheme of pocket money and medical-kits. But none of the subject of this study was provided with the service for funeral related costs. Though according to its report, $TBCS^{+}$ had covered the funeral costs for the families of 20 deceased persons in the last five years, no respondent included in the study.

Therefore, the four services (the provision of HBC services, non-medical kits, IGAs and capacity development trainings and members' representation and rights protection) were all inclusive, non-restrictive and non-discriminatory and of whom all members benefit. For instance, even each of the 78 volunteer HBC service providers themselves had serviced by another fellow volunteer service provider. But the remaining four services (emergency care & transportation cost, funeral related costs, nutritional support, and pocket money and medical-kits) were not all inclusive and based on certain pre-conditions. For instance, to get pocket money and medical kits one has to be a volunteer HBC service provider; to get nutritional support the PLHIV had to be chronically ill or/ and bed- ridden patient or his/her CD4 count reduced; to get the transport and emergency cost the beneficiary had to present referral certificate to health institutions outside Assosa for further medication or incurred medical expenses for emergency cases.

4.2.2 How Long the Members Received the Services from TBCS^{+}?

According to the relevant documents of the organization, TBCS^{+} was founded some 12 years ago (in 2002) by five founding members and have been serving its members and other non member beneficiaries in various forms. As it is shown in the *Table 3* below, most of the respondents 26(65%) have been receiving the services of the organization for more than 5 years. The other 5(12.5%) of the respondents received the services for less than 3 years and 9(22.5%) of the respondents obtained the services from 3 to 5 years. However, the extent and the magnitude of the services of the organization vary from year to year and its support reaches its climax after the organization has begun to implement the Global Fund supported projects since 2009.

Table 3: How Long the Members Received the Services

Years	Frequencies	Percentage (%)
<3 years	5	12.5
3-5 years	9	22.5
>5 years	26	65
Total	40	100

4.2.3 The Health Contribution of the Services

One of the main reasons why PLHIV associations have been established is to improve the health conditions of PLHIV through the provisions of number of services to their members and beneficiaries. Therefore, this paper tried to investigate whether the services of TBCS^{+} contribute to improve the health of its members/beneficiaries or not.

As shown in *Table 4* below, all of the 40(100%) of the respondents acknowledged the health contribution of the services they had provided by TBCS^{+}.

Table 4: The Health Contribution of the Services

Health Contribution	Frequencies	Percentage (%)
Yes	40	100
No	0	0
Total	40	100

The cases of some informants presented as follows:-

A respondent code 01, a divorced CSW and aged 26 explained that:

> *"It is difficult to express in words the benefit I got from TBCS$^+$ and the health improvement I had brought due to its support. In Assosa, I was a stranger without relative and unfortunately I failed ill due to AIDS in late 2013. As I was on the verge of death and my death might be comparable with a death of a dog. Fortunately, the people of TBCS$^+$ heard the news, took me to the hospital, mobilized resources from the staff members, members of the association, training participants etc to cover my expenses. They also encouraged and advised me to take my medicine properly. TBCS$^+$ changed my mentality and spirit and develop the belief of living long as anyone. Currently my health had greatly improved and now I had pursued my duty. Secondly, the blanket and bed sheet which TBCS$^+$ had provided me saved my life from cold. In addition, by now I believed that I had a guarantor, I felt secured. If I had become sick they would care and provided support for me, even if I had die, they would bury my dead body*."

A Code 03, a man with the age of 37said that:

> *"For many years (starting from the time when I was a high school student) I was a hotel manager. That was the reason why, I have become addicts to alcohol and khat. Due to the complication of addiction, I was an anemic. For three times, I admitted to hospital and referred to Addis Ababa for higher treatments. Thanks for my association, TBCS$^+$, for covering my medical expenses and saved my life. Now my health condition had improved, I was serving as a daily labor in construction works. To help me to revoke addiction to Khat and its complements, TBCS$^+$ let me participated training on the effects of addiction to Khat and its complements and got other supports. So, I stopped chewing khat and my health improved and freed from the anemia."*

The data gathered from the board and staff members of the organization through semi-structured interviews also reflected that the services provided by TBCS$^+$ had been scoring improvements in

the health conditions of the beneficiaries. In conclusion, the services of TBCS^{+} had brought about improvements on the health conditions of the beneficiaries and these services had to be strengthened in scope and depth.

4.2.4 The Economic Contribution of the Services

Bringing economic empowerment and strengthening the economic status of the PLHIV is another most important rationale for the establishment of the PLHIV associations. Concerning the economic contribution of the services of the organization, as it is shown under *Table 5* below, all 40(100%) of the subjects of the study stated that the supports they got from TBCS^{+} contributed to improve their economic status and lives, though the degree of the contributions vary from individual to individual.

Table 5: The Economic Contribution of the Services

Economic Contribution	Frequencies	Percentage (%)
Yes	40	100
No	0	0
Total	40	100

According to the respondents' reflections, some had begun to run their own private business, some others had got job opportunities and earning their incomes, others enabled to procure materials and even some opened their own bank accounts and began saving for future. So, the supports contributed to improve the lives of the beneficiaries, though these services need furtherance to bring major and fundamental changes in the lives of the beneficiaries.

As an example, the respondents reflected the contribution of the organization as follows.

Code 02, an ex-soldier with the age of 38 elucidated that:

> *"By being the member of TBCS^{+}, I got regular job (I became a security officer and I had been serving as the volunteer HBC provider for which I was earning*

Birr 250.00 per month. TBCS+ also provided me with number of trainings that helped me to bring attitudinal changes and broaden my outlooks on various issues as well as to get additional incomes. Thus, by now I procured TV, tape, bed etc. The provision of the non-medical kits also helped me and my family to protect ourselves from bad weather conditions and to expend the money for the purchase of these materials for other purposes. Previously I used khat, alcohol, cigarettes. But now I stopped all and concentrate on my business. TBCS+ had become my energy and power to work and live."

Code 06, a 26 years old female petty enterprise owner said that:

"I was born in Woliso and had grown and learnt in Dire Dawa. While I was a night student, I was abducted by a man in uniform who took my virginity. I married him without my consent and became the victim of the virus. Later, I came to Assosa and joined TBCS+ in 2011which helped I to bring drastic changes my life. Soon, I received Small Business Management Skills training and the startup capital amounting Birr 4000 .00.On the basis of my own business plan, I opened a retail shop. Currently, I was taking care of my two children alone (because I separated from my husband) and equipped my home with the necessary furniture and equipments with the income I was earning from the shop. In addition, I had some 3,050.00 Birr in Bank and gold ornament amounting about ETB 5,000.00. So, TBCS+ had saved me from becoming a beggar or a CSW."

The Urban Garden Extension Officer of the organization highlighted the economic contributions of the services TBCS+ as follows:

"98 persons including 58 People Living with HIV (PLHIV) women and 40 OVC (20 females and 20 males) through their guardians) had been involved in urban gardening. They had provided with agricultural instruments and other inputs, pipe water to irrigate the vegetables, capacity building trainings, technical support from the Extension Officer, Advisory Committee and Conflict Management Board. The beneficiaries formed their own Cooperative Association named Andinet (Unity) Urban Agriculture Cooperative Association which was registered by the concerned government organ and joined the Assosa Woreda Farmers' Cooperatives Union. So, they had enabled to produce various kinds of vegetables like cabbages, potatoes, tomatoes, onion, garlic, redroots etc during the winter season and they were growing maize the rainy time (because the rainy season is unfavorable for vegetables). Therefore, in one hand they enabled to feed themselves with balanced diets and on other hand they provided vegetables to the urban dwellers and generate additional incomes. This initiative helped to strengthen the morale and the working behavior of PLHIV. The members have planned to open poultry and grain mill by taking credit from the union."

To sum up, the support of TBCS^{+} had contributed for the economic empowerment of the members of the organization, although the support was not to be believed adequate in changing the lives of all members. There were many members of the organization who had not effectively and properly utilized the IGAs schemes and still led fragile lives.

4.2.5 The Contribution of the Services in Promoting Social Relationship

The formation of PLHIV associations is vital to promote the social interrelationship of the PLHIV and to fight and curb HIV and AIDS related stigma and discrimination. As it is shown under *Table 6* below, all of the 40(100%) informants of the study confirmed the contribution of the services in promoting their social interrelationships.

Table 6: The Contribution of the Services in Promoting the Social Relationship of the Members

Contribution for Social Relationship	Frequencies	Percentage
Yes	40	100
No	0	0
Total	40	100

TBCS^{+} had contributed in developing the confidence and the morale of its members and helped them to value themselves and to communicate, interact and participate in all forms of social activities. They actively interacted with PLHIV (among and between their fellow members) and with the larger members of the community without fear and isolating themselves from the community. When the researcher of this study gathered the data (conducting the individual interviews and the FGD), he observed their feelings and found that interviewees and the participants of the FGD actively participated without fear and with full confidence.

The participants of the study reflected the presence of wide difference in their social interaction in pre and post membership period and support of TBCS^{+}. Most of the respondents stated that in

pre-membership and prior to the provisions of the services "they had lived isolated lives and they were fearful to interact and participate with the community members." But the provision of the services changed the scenario. They said that "these services helped them to develop their confidence and hope as well as to promote their interrelationships and interactions not only with PLHIV but also to increase their participation in self- help social groups like Iddirs with the wider community.

As an example some of the informants declared the contribution of the services in promoting their social relationships as follows:

Code 05 a woman with the age of 29 explained that:

> *"I had been a member of self-help group (Iddir) established by PLHIV. We meet every Sundays; share our feelings, sorrows, happiness and other social and economical issues and visite patients and other fellow PLHIV members. This interconnection helped to promote our pleasure and happiness and to reduce the psycho-social impacts of the epidemic. So, the organization helped us to have strong social bonds and linkages among PLHIV. These types of contacts helped us to break the fears of stigma and discrimination. One serves as a moral arm for the other fellow PLHIV."*

Code 40 a man with the age of 37 declared that:

> *"Formerly I concealed my status from my neighbors, friends and relatives, I feared everybody suspecting that he/she knows my HIV positive status and I isolated myself from the community and social issues. Thus, I felt unhealthy and unstable and I was in psychological trouble and anxiety. But, now I feared nothing and anyone. So, I exposed myself and teach the public about HIV and AIDS with the motto "Save Others, Enough with Us!" I had developed the belief that as far as I followed the principle of positive living with the virus, I would live long that God bestows me to live. I taught this principle to those whom I had entrusted to provide HBC and to other PLHIV. I had an Iddir of neighborhood and I was an auditor of the Iddir. The Iddir members both PLHIV and others supported each other without discrimination."*

4.2.6 The Contribution of the Services in Bringing Attitudinal Changes

To the question whether the services provided by TBCS$^+$ have contributed in bringing attitudinal changes or not, all the 40(100%) respondents replied in support of the contribution of the services (*see Table 7 below*).

Table 7: The Contribution of the Services in Bringing Attitudinal Changes

Contribution for Attitudinal Change	Frequencies	Percentage (%)
Yes	40	100
No	0	0
Total	40	100

As examples, some sample explanations of the informants presented underneath.

Code 011, a man with the age of 32 stated his own attitudinal changes as follows:

> *"I myself had brought dramatically attitudinal change to myself and concerning the virus. At the time when I recognized my status, I was disturbed, became fearful and ran away from everyone; I thought I would die soon. But now I felt strong enough and I believed that I would live for long time. I dared to do everything to sustain my life even by eating kolo."*

Code 33, a woman aged 43, replied that:

> "*When I knew my HIV+ status, I thought that I would not live even a month. And I encountered with mental upset and turmoil, fear and anxiety and psychologically disturbed. I isolated myself and I became lonely. But when I met TBCS$^+$ and got advices, consultations and shared the feelings and experiences with other members, I began to cool down. As result of the consultations and sharing of experiences, I had felt healthy and I began to believe and hope that I would live a longer life and HIV could not hinder me from doing everything. Now, I had my own job, I carried out it without fear. I had established my own family and supported them."*

The project officer of TBCS$^+$ summarized the overall contributions of the organization in improving the social relationships of the members and bringing attitudinal changes as follows:

"The services had helped the beneficiaries to be fearless i.e. they didn't fear anybody because of their HIV status; they simply exposed them to non-reactive people; they developed positive living with the virus. PLHIV became psychologically and mentally strong. They built good and smooth social relationships with Community Based Organizations (CBOs) like Iddir. The number of bed ridden patients and death rate associated with HIV decreased. They took their medicines and diets properly. Their motivation to engage in IGAs had increased. Finally, the impacts and the prevalence of the epidemic began to decline from year to year due to the improvements of the social relationships of the PLHIV and their attitudinal changes."

So, it is concluded that the services of TBCS$^+$ had helped to create a great deal of opportunities in bringing attitudinal changes among the members of the association.

4.2.7 Beneficiaries Current Situation

As it is indicated in *Table 8* below, concerning the question of whether the beneficiaries or/and their family members current situations would have deteriorated or not, if they were not provided with the services of TBCS$^+$; all the 40(100%) participants of the study replied that their condition would be deteriorated and even some stated that they might not live today.

Table 8: Beneficiaries Current Situation

current status of the Beneficiaries	Frequencies	Percentage (%)
Improved	40	100
Worsened	0	0
No Change	0	0
Total	40	100

The reflections of some of the respondents presented below.

For instance, Code 01 said that; "when I was sick in late 2013, I expected for my death. If I had not provided with the support of TBCS$^+$ I would not live by now. You could not get me today. I planned to leave my current work (CSW) and I want to run my private business. I will say nothing but God bless TBCS$^+$, its members and staff."

Code 38, a former CSW explained that, " if I were not taken to hospital and provided with the advices, care, support and fostering by the members of TBCS+, I might die soon and I had been forgotten; I might not replace myself(bear child) and lead the current life."

4.2.8 The Effects of the Services in Reversing the Prevalence of the Virus and the Impacts Of HIV and AIDS

The main essence behind the establishment of the associations of PLHIV is combating the spread of the virus and reversing the impacts of the epidemic. Accordingly, as it is shown in *Table 9* below, all of the respondents recognized the contributions of $TBCS^{+}$ in reversing the impacts and prevalence of the epidemic.

Table 9: The Effects of the Services in Reversing the Impacts and Prevalence of the Virus

Reversing the impacts of HIV and AIDS	Frequencies	Percentage (%)
Yes	40	100
No	0	0
Total	40	100

The testimony of some of the respondents' on services contribution in curbing the impacts and prevalence of the epidemic explained as follow.

Code 04, a female with the age of 27, said that:

> *"The services of $TBCS^{+}$ have contributed to curb the impacts and prevalence of HIV and AIDS. $TBCS^{+}$ has raised the awareness of PLHIV to protect themselves from OIDs, taught the advantageous of using condom, adherence to ART, and advised the members to make their family members to be tested of HIV. So, it has helped to promote the habit of HIV testing. Members had encouraged their partners and family members to have HCT. When members unhide themselves, they freely talked about the epidemic publicly and propagating the motto of "Save others, Stop with us" and they helped to raise the awareness level of the*

community. This incident helped not only to decrease the prevalence of the epidemic but also minimize stigma and discrimination."

Code 08 said that:

"From TBCS+, members got not only blankets, nutritional supports, SBM and Vocational Trainings, startup capital etc but also it imparted about positive living with the virus. The members themselves learnt and shared ideas one to another how to keep his/her hygiene and sanitation, properly use the medicine and nutrition, protect his/her from OIDs, STIs, to use condom even with one's spouse. In addition, it helped members to refrain themselves from spreading the virus to others intentionally or negligence."

One of the participants of the Focus Group Discussion (FGD) commented that:

"The services of TBCS$^+$ had great values in curbing the impacts and spread of the epidemic. A great number of the organization members had gotten HBC services and palliative cares which helped them to relieve from their bed-ridden situations and lead a normal lives. Mostly when PLHIV had informed about the HIV status, they became hopeless, but when they had joined TBCS$^+$ and received the services they began to drop the dilemma of hopelessness, grieves and sorrows and became hopeful. Other fellow members had attended Small Business Management skill and vocational trainings and provided with start-up capital and involved in IGAs. The members also helped to make aware the community members to save themselves from the HIV like not to get married without pre-HIV test, to use condom etc. Even we members had learnt about the family planning."

Code 30 a man with the age of 35, replied that "if we were not formed our organization and learnt and assisted each other, we would not unhide ourselves, make known our status to the public, and teach the community. Contrarily we might transmit the virus to others by hiding ourselves and we might revenge our community members."

The responses of the board members and the staff members of TBCS$^+$ signified the contribution of the services of the organization in empowering the socio-economic and health status of the members and the beneficiaries, bringing attitudinal change, and curving the spread of the virus, i.e. in reversing the impacts and prevalence of the epidemic.

For instance, the field officer highlights the contribution of each service as follows:

> *The HBC services had helped the beneficiaries to be psychologically and mentally strong and resilient to HIV and AIDS; take their ART timely and adhere to it; accept and develop the belief of positive living with HIV and AIDS; increase their awareness to Opportunistic Infectious Diseases (OIDs) and Sexually Transmitted Infections (STIs); keep their family manageable; increase their awareness about Prevention of Mother to Child Transmission (PMTCT) services and keep their hygiene and sanitation so as to improve their health situation; use condom and make their family members get Voluntary Counseling and HIV Test (VCHT). Whereas, the provisions of emergency care and transportation cost had helped the beneficiaries to cover their medication/ treatment and transportation costs at the time of referral to distant health institutions like in Addis Ababa.*

4.2.9 The Benefits of the Services of TBCS^{+}

According to the interviewees of the study and the responses of the board and staff members, the benefits or advantages of the services of TBCS^{+} include. The services had helped to:-

- Bring attitudinal changes among the beneficiaries and helped to build their confidence and hopes. The members have begun to consider HIV and AIDS like any other diseases.
- The HBC services have helped to enable the bed- ridden PLHIVs to recover from their illness and lead healthy lives. The benefit of the HBC services were too high especially for persons without relatives, the strangers and the poor; because it has been provided for any PLHIV who was in seek of the support regardless of racial, religious, linguistic, social, economic background, age, sex, region etc. Even when the family members, relatives, friends and neighbors had failed to provide care and support to PLHIV, (especially for the bed- ridden PLHIV patients) the TBCS^{+} volunteer care givers provided the care and supports for such individuals.
- Lessen stigma, discrimination, and social exclusion.
- Serve as means and venues of information, experience, feeling, emotion sharing.

- Strengthen social interrelationships among the PLHIV, improve their engagement in social affairs, enable PLHIV to be self- reliant and confidence to run their own businesses and lead secured lives.
- Serve as means to mobilize fund from the PLHIV and supporting the financially weak fellow members so as to support to cover the costs for house rents, medication etc.
- Promote the participation of the PLHIV economic activities and reduce poverty and dependency among PLHIV. It addresses the needs and priorities of members.
- Enable to know the whereabouts and the status of fellow members.
- Provide funeral services for the dead PLHIV and reduce the number of ART defaulters.
- Enable PLHIV to bear HIV negative children/ reduce the transmission of the virus from mother to child and promote VCT among the family members of the PLHIV.
- Drastically reduce the transmission of the virus to negative people for these services helped the PLHIV to expose them and teach the public.
- Build the belief that PLHIV can live long, promote the belief of positive living with the virus and reduce HIV and AIDS related death rates.
- Promote the beliefs among the PLHIV that they would do and increase their income like that of non- reactive people.

4.2.10 The Limitation of the services

Though the services of the organization had been scoring number of remarkable achievements and bringing incredible results in reversing the impacts and prevalence of the epidemic, the provisions of the services and the works of the organization were not free of limitations. Some of the major critical issues that need consideration include.

- Sometimes, the Vocation Trainings and the IGAs schemes had not taken in to considerations the capacity, interests and needs of some of the beneficiaries. So, there were many PLHIV, though they were provided with trainings and the startup capital, they wasted the fund and remained dependent and expectant of next aid.
- The newly recruited HBC providers had not yet provided with capacity building trainings. So, it was difficult to except efficient services delivery without proper training.
- Almost all respondents complained that the income sources of the organization was limited and insufficient to address the diversified needs and interests of the members, though the organization had been striving and working towards addressing the needs of the members and tries to increase its sources of fund from time to time.
- The inability of the organization to get land from the Assosa Municipality for the organization's office construction and houses building for homeless members, though the organization succeeded to get land for the construction of shops (it had constructed and rented two shops at the City's main commercial place, Friday Market), for urban agriculture and construction of grain mill (the grain mill house had not yet constructed).
- Although number of services and supports had provided by $TBCS^{+}$ and other stakeholders, there were many PLHIV who could not break out of dependency. Many of the beneficiaries failed to use the opportunities like the Small Business Management and Vocational Trainings to manage their business or wisely and properly use the IGA schemes. They consumed the startup capital for their immediate problems.
- Budget shortage. Though the number of the members had increased from time to time the organization's income and the fund for HIV and AIDS is not increasing correspondingly.
- The money for referral support was too insignificant to cover the expenses incurred.

4.2.11 The Most and Least Essential Services of TBCS+

Concerning the relevance of the services of the organization, almost all informants' agreed that all services were relevant, though finally they prioritized the three most important services and identified the three least essential services. As it is seen from *Table 10* below, from the all 8 services of the organization, HBC services, IGAs and capacity development trainings, and provision of non-medical kits were prioritized as the three most essential services and selected by 34(85%), 31(77.5%) and 16(40%) of the respondents respectively. While the provision of funeral related cost, emergency care and transport cost, representation and rights protection of members were leveled as the three least essential services and selected by 3(7.5), 4(10%), and 8(20%) informants respectively. Whereas nutritional support and provision of pocket money and medical kits for the HBC providers were ranked in between and chosen by 14(35%) and 10(25%) repliers respectively.

According to the respondents, the reasons why most of the informants chose HBC services as the first most important services was that it had made the PLHIV more aware of the positive living with the virus, helped to provide care and support to the bed- ridden AIDS patients and recover from their sickness. In general, it was regarded as the main instrument to curb the impacts and the prevalence of the epidemic. The reason why the IGA services were chosen as the second most important services was that the schemes are instrumental to reduce the dependency rate of the PLHIV, promote not only the economic status of the beneficiaries but also builds the morale and confidence of the PLHIV and help to reduce stigma and discrimination. While the provision of non-medical kits were chosen as the third essential service for the service itself was accessible to almost all of the beneficiaries, helped to protect the AIDS patients from bad

weather conditions and saved the beneficiaries from expending their limited resources for the purchase of such materials.

Table 10: The Most and Least Essential Services

Name of Services provided by TBCS+	Frequencies	Percentage (%)
1.Home Based Care services	34	85
2. IGAs and capacity development trainings	31	77.5
3. Provision of Non-medical kits	16	40
4. Nutritional support	14	35
5. Provision of pocket money and medical-kits	10	25
6.Members representation and rights protection	8	20
7. Provision of emergency care & transportation cost	4	10
8.Provisions of funeral related costs	3	7.5

In conclusion, although HBC, IGAs and provision of non-medical kits are selected as the three most essential services, it does not mean that the other services are irrelevant. Each of the service has its own role in curbing the impacts and spread of the virus and empowering the beneficiaries.

4.2.12 Addressing the Needs and Priorities of the members

Concerning the issue of addressing the needs and priorities of the target groups, as it is revealed in *Table 11* below, 37(92.5) replied "yes" and the remaining 3(7.5) replied "no". The latter 3 respondents explained the reasons why they said "no" is that, though the organization has been working towards addressing the needs and priorities of the members, it could not satisfy their needs and priorities fully. Because, the number of the members had increased from time to time and their demands were growing and diversified correspondently but paradoxically the

association had limited financial sources to address the members' needs and priorities. This idea has also got the support of the project officer of the organization.

Table 11: Addressing the Needs and Priorities of the Target Group

Addressing the needs and priorities of the members	Frequencies	Percentage (%)
Yes	37	92.5
No	3	7.5
Total	40	100

4.2.13 Realization of Organizational Objectives

The organization has five objectives. These are:-

1. Reduce vulnerability and mitigate the impacts of HIV/AIDS on PLHIVs and their families.

2. Reduce ART defaulter rate among ART attendant by 15 % at the end of 2015.

3. Improve the nutritional and income status of PLHIVs (mother support group) and OVCs.

4. Strengthen the implementation capacity of the association members and its constituents.

5. Mobilize required resource for the execution of planned activities of TBCS.

Table 12: Realization of Organizational Objectives

Realization of objectives	Frequencies	Percentage (%)
Yes	40	100
No	0	0
Total	40	100

As it is shown in *Table 12 above*, all of the respondents expressed that TBCS^{+} had been working towards the realization of its objectives. According to their responses, TBCS^{+} has helped to:-

- Create and raise the awareness levels of the members on positive living with the virus.
- Create job opportunities for members and beneficiaries through group and individual IGAs, urban gardening agriculture, etc.
- Provide nutritional support so increase the nutritional and health status of PLHIV.

- Support women and OVC to get better diet and income by engaging them in urban gardening and serve the poor of poor of the community and reduce dependency.
- Provide awareness raising education, psycho-social support, startup capital, HBC services etc to PLHIV so as helped to reduce the impacts and prevalence of the epidemic.
- Provide support and palliative care for those who had no relatives and supporters.
- Provide social, emotional, psychological and material supports without discrimination
- Strive for the protection of the rights of the members. It helped the voiceless to be heard as a result of forming their association.
- Provide the members with recommendation and supportive letters.
- Provide funeral services for the dead PLHIVs.
- Help to reduce HIV and AIDS related discrimination and stigma.
- Create venues for the PLHIV to assist each other like in time of death and sickness.
- Built the trust, confidence, morale, motivation, inspiration hopes etc of the members.
- Contribute to the reduction of the prevalence of the virus by reducing new infections (according to the Ethiopian Sub-National Estimate the overall regional prevalence rate was lowered to 1.1% in 2013).
- Develop the belief of caring for other negative people.
- Prevent the PLHIV from other STIs and OIDs by teaching the members to use condom, adhere with ART, hygiene and sanitation, proper eating habits etc.

According to the organization data the number of the clients on ART had increased from time to time: 147(with 3 defaulters) in December 2010; 525 (with one defaulter) in December 2012; 620 (with 2 defaulters) in June 2013; and 841 with no defaulter in June 2014. So, the number of ART defaulter is insignificants and mostly due to death.

The organization widened its resources bases and increased its annual incomes. For example, prior to 2012 the organization only implemented one project financed by the Global Fund through Network of Benishangul Gumuz Charitable Societies to PLHIV Consortium ($NBGP^+$). In 2012, it implemented two projects and in 2013, 3 projects. In 2014 the organization has been implementing four projects. The annual income and the amount of budget administered by the organization had increased from year to year (in 2011, it administered Birr 254,955.00; in 2012, Birr 944,966.00; in 2013, Birr 871,045.00, and in 2014 it is running Birr 1, 015984.69).

It is worth mentioning to quote the statements of one of the board member (who works as Public Relation Officer at Regional HAPCO). He highlighted that:

> *" $TBCS^+$ had helped PLHIV to solve their common problems together, create job opportunities, bring attitudinal changes, to build close social relations, reduce the prevalence of the epidemic, and prevent the transmission of the virus from mother to child. It had helped to provide information and educational support to PLHIV to use their medicines and diets properly on time, to effectively and actively participate in socio-economic affairs and developmental initiatives, refrain themselves from retaliating others and spreading the virus, support the OVCs. It broadened its financial source- for instance; currently it had received new fund from the Benishangul Gumuz Development Associations Network (BGDAN) and working against addiction to khat and its complements for the wellbeing of the community, especially the youths". $TBCS^+$ had established good relationship with various stakeholders and promoting partnership and networking. For instance, $TBCS^+$ is the member of the two regional networks-BGDAN and $NBGP^+$."*

The attainment of its objectives and addressing of its members' needs and priorities was also accepted by chairperson of the organization's Board of Directors. The Chairperson said that:

> *"To me, the $TBCS^+$ had been working towards meeting the members' needs and realizing its objectives. The results were manifested by the member themselves. The interest, attraction and support of the members to the organization as well as the unity, solidarity, learning and sharing of information and cooperativeness of the members among each other had been enhancing from time to time. Currently when the members were called for meetings each and every member would avail him/her, give constructive ideas, and listen to each other than before. They had*

highly realized that the formation of their organization and coming togetherness helped them to be heard and getting recognitions by different organs. TBCS+ had been working towards diversifying its income sources and mobilizing more funds from different sources like shop renting, membership contributions and projects and benefiting more its members than before."

Therefore, from the responses of the interviewees and reflections of board members, it is possible to conclude that the organization is working towards to the realization of its objectives.

4.2.14 Satisfaction of the Members on the Services of TBCS+

Regarding the issue, whether the respondents had satisfied with the services of the organization or not, as it is revealed in the *Table 13* below, 39(97.5%) of the informants reported that they had satisfied with the organization's services. But 1(2.5%) of the respondent chose no.

Table 13: Satisfaction of the members to the Services of TBCS+

Satisfaction of the members with the services	Frequencies	Percentage (%)
Yes	39	97.5
No	1	2.5
Total	40	100

As examples the reflections of some of the respondents presented as follows:-

*C*ode 01, explained her satisfaction as follows:

"I was highly satisfied with the services of TBCS+. Because it had provided the services for all PLHIV regardless of region, religion, sex, age, affinity. For instance, I came here from distance place and I was stranger to the town and the community and even to the organization but TBCS+ had fostered me as a parent. So, why not I had satisfied with the services of the organization which helped me at the time when I was sick and on verge of death."

A Code 08, explained his satisfaction as follows, "when I heard my HIV positive status, I left my occupation (I was a government police office). At the time when I left my occupation, I hadn't

any cent. But with the support and advice of the organization, I forget my dissatisfaction and began to live a peaceful life with my family."

The reflections of the Project Officer, the Executive Director, the member of the board of directors and other staff members maintain the above views of the beneficiaries.

The Executive Director said that:

> *"The members and the beneficiaries satisfied with the works of TBCS$^+$. They regarded the organization as their mothers and fathers and life blood. When the issue of TBCS$^+$ had raised, all stood together as swarm of bees. They stood together and no one would let to negotiate on the issue of TBCS$^+$. They kept the organization as the pupil of their eyes."*

The finance officer replied that, "The members and the beneficiaries had good insight and view to the organization, that was why most of the members paid their membership contributions on time and regularly, and convened when they were called for meetings."

However, code 11 reflected his view in contrary. He said, "I had not yet satisfied with the services of the organization. The services were still at subsistence level. Most of the members were dependent on support of the organization. I expected all of the members to be self-reliant."

4.2.15: The Alignment of the Services with HIV and AIDS Policies and Strategies

For the question, do the services of the organization align with HIV and AIDS policies, strategies guidelines, etc? All the interviewed board and staff members provided positive replies. For instance, the project officer of the organization rejoined that "the services of TBCS$^+$ had aligned with HIV and AIDS policies, strategies, guidelines etc. In the national HIV and AIDS Guideline, there are seven services that have to be provided to PLHIV and the services of TBCS$^+$ were related with them. These services include Food and nutrition support; IGA/economic

strengthening; Legal protection; Shelter and care support; Educational support; health care support; and psychological support."

As it is stated in the above sections, TBCS^{+} 's intervention areas were correlated with the WHO four main domains of HIV and AIDS care and support services(shown under fig. 2 below).

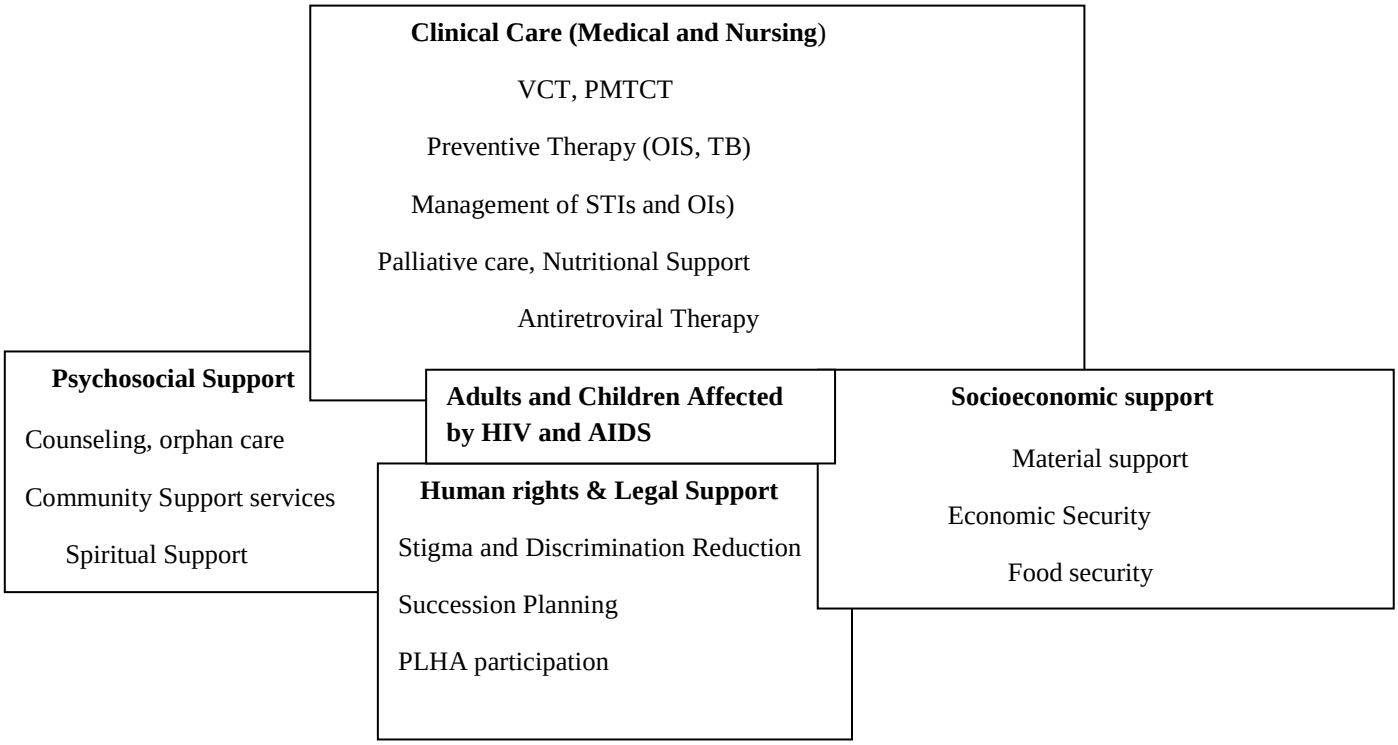

Fig.2: The Four Main Domains of HIV and AIDS Care and Support Services (Source: WHO, 2004:6 quoted by Lemlem, 2013:17)

The WHO 2007 document declares that, "to address the needs of PLHIV, the HIV and AIDS care and support program should take in to consideration the following objectives". These are:-

1. Ensuring equitable access to diagnosis, health care, pharmaceuticals and comprehensive support services
2. Reducing morbidity and mortality from HIV and AIDS and related complications;

3. Promoting opportunities for preventing HIV transmission with the delivery of care and support services; and
4. Improving the quality of life of both adults and children living with HIV and AIDS and their families.

As it has stated in the aforementioned sections, the interventions and services of TBCS^{+} have associated with the above four objectives of the WHO.

The intervention areas of TBCS^{+} had also correlated with the key intervention areas in which the national HIV prevention response intends to focus. According to HIV Prevention Package, the national HIV prevention response intends to focus on community conversation(CC), HIV Counseling and Testing (HCT), prevention of mother- to- child transaction(PMTCT), infection prevention(IP), post-exposure prophylaxis(PEP), condom promotion and distribution, sexually transmitted infections(STIs) prevention and control and provision of ART(FHAPCO, FMOH HIV Prevention Package, 2011:3).

In this regard, TBCS^{+} had directly involved in the implementation and provisions of some of these services. Nevertheless, though the organization is not directly involved in the provision of some of these provisions, it facilitates and makes aware the members/beneficiaries to use the services in the health centers. For instance, the organization had directly taught the community in general and the members and the beneficiaries in particular about the virus, HTC, the condom use, the PMTCT, IP, PEP, STIs and use and adherence to ART through CC and other methods like HBC services in order to make the community and the members to be aware of the services, and where they could get and how to use these services.

4.2.16 TBCS^{+} Relationships with Stakeholders

Concerning the issue of the relationship of the organization with the stakeholders, all of interviewed board and staff members of the organization ensured the presence of good, smooth, cooperative, interactive and workable relationship between TBCS^{+} and its stakeholders. According to the reflection of the Project Officer *"all the stakeholders had smooth relationship with the organization. Some of the stakeholders had been represented as board members, others involved in project advisory committees, and some granted funds, and even some others provided technical and material support to TBCS^{+}."*

Similarly the board member from Regional HABCO described that *"Formerly a great number of originations and government offices left the issues of HIV and AIDS as the affairs of HAPCO, Health Offices and PLHIV Associations only. But currently a great number of entities began to support PLHIV associations, mainstream HIV and AIDS and establish good relationship with TBCS^{+} and assisting the organization. However, the support to the PLHIV associations, the mainstreaming process and supporting the HIV Prevention activities have to strengthen."*

4.2.17 Major Challenges in Providing Services

On the basis of the replies of the respondents the major challenges of the organization can be summarized as follows.

- ✓ Some of members want to be included in all of the IGA schemes/ supports repeatedly without giving chance to other fellow members. It was also distressing that they wanted to be included in the scheme not to use the fund for the IGA scheme for its intended purpose and bring change in their lives but to use the

money for their immediate needs. This incident had its impacts in creating complication and work burden on the organization.

- ✓ Formerly financial support had provided to the PLHIV to encourage them to start ART service and this support had created the tendency of dependency and expectancy for direct financial support among the PLHIV instead of involving in IGA program and bring sustained change in their lives.
- ✓ The financial and material shortages had its own adverse effects on the organization's effective and efficient service delivery.
- ✓ The failure to get urban land for the organization's office construction and houses building for homeless PLHIV.
- ✓ Some members' failure to avoid the tendency of dependency and properly use the IGA Schemes. They had low interest to properly use the IGA schemes for the intended purposes.
- ✓ In the recent past the support for HIV prevention is low among the donors and partners. So, the TBCS^{+} had limited interventions on the prevention activities.
- ✓ The failure of some of the IGA schemes to consider the interest and capacity of the beneficiaries.
- ✓ Reluctance of some of the members to involve in group IGAs.

CHAPTER FIVE

V. DISCUSSION OF THE MAJOR FINDINGS

This study attempted to assess the contributions of People Living with HIV (PLHIV) associations in empowering PLHIV and reversing the prevalence and impacts HIV and AIDS with special emphasis of Tesfa Bilichita Charitable Society to PLHIV (TBCS+) of Assosa District of Benishangul Gumuz Regional State (BGRS), in Ethiopia.

Similar to other related review documents, the socio- demographic data of the study showed that the main victims of the epidemic are the productive and reproductive age groups, though the virus does not leave any age group of the community. The pertinent organizational data of TBCS^{+} also revealed that the majority of the members (58.7%) and the service clients (67.4%) of the organization are females. Similarly, according to the USAID and World AIDS Day reports, in Sub-Saharan Africa, around 59% of those living with HIV are female (UNAIDS, 2011, World AIDS Day, 2011). So, women are more vulnerable to the HIV and AIDS and victims of its socio-economic impacts than their male counter parts. The finding of the study showed that, the educational level of the majority of the respondents was very low. So, these individuals could not get better job opportunities to lead better and sustained lives. The finding of the study also showed that 60% of the informants earned low income (a monthly income less than ETB 1,000.00 or less than USD50.00.) It is known that HIV and AIDS lower the income levels of the PLHIV (FHAPCO, 2011:10).

The findings of this study revealed that the services and intervention areas of the organization had aligned with the HIV and AIDS policies, strategies, guidelines etc. For instance, the services provided by the organization had directly or indirectly aligned with the seven interventions areas

that the national HIV and AIDS guideline expected to be delivered to PLHIV. These seven key intervention areas are food and nutrition support; IGA/economic strengthening; legal protection (members' right protection and representation); shelter and care support; educational support; health care support; and psychological support. Moreover, the services of $TBCS^{+}$ had correlated with the four main domains of HIV and AIDS Care and Support Services(Clinical Care/Medical and Nursing, Psychosocial Support, Socio-economic support and Human rights & Legal Support) proposed by the WHO (2004) to be delivered to adults and children affected by HIV and AIDS. Thus, though $TBCS^{+}$ does not directly provide the Clinical Care/ Medical and Nursing support in health institutions (as it has no the institution), its HBC service providers provides home to home clinical care and nursing service, teach and help the clients to get the services in health centers. The intervention areas of $TBCS^{+}$ had also correlated with the key intervention areas in which the national HIV prevention response intends to focus- on community conversation (CC), HIV Counseling and Testing (HCT), prevention of mother- to- child transaction (PMTCT), infection prevention (IP), post-exposure prophylaxis (PEP), condom promotion and distribution, sexually transmitted infections (STIs) prevention and control and provision of ART (FHAPCO, FMOH HIV Prevention Package, 2011:3).

The result of the study revealed that the services of the organization had contributed in empowering the members of the organization and reversing the impacts and prevalence of HIV and AIDS. The finding depicted that the services of the organization had contributed in improving the health conditions, the economic status (income), the social relationships of the beneficiaries and bringing attitudinal changes among them. Other literatures recognized the socio-economic supports of PLHIV associations to PLHIV(Alula et.al 2008, Country Progress Report on HIV/AIDS Response 2012,) The services of the organization contributed to help the

service clients to consider HIV and AIDS like any other diseases; the bed- ridden PLHIV to recover from their illness and lead normal lives; to get care and support (especially for the bed ridden PLHIV patients); to lessen stigma and discrimination and avoid social exclusion; serve as means and venues of for the sharing of information, experience, feeling, emotion etc. These contributions of services TBCS^{+} to PLHIV are almost matched with the contributions mentioned in Alula, et.al 2008, http://www.worldaidscampaing .org, Country Progress Report on HIV/AIDS Response 2012, Alemu 2002, Ayalew 1999, Ethiopian Health Development Journal, 2003).

The findings of the study also showed that the services provided by TBCS^{+} have helped to serve as means to mobilize fund from the PLHIV and support the financially weak fellow members so as to support to cover the costs for house rents, medication etc; enable to know the whereabouts and the status of fellow members; provide funeral services for the dead PLHIV; reduce the number of ART defaulter; enable HIV positive parents to bear HIV negative children/ reduce the transmission of the virus from mother to child; build the confidence, trust and hopes of the PLHIV; address the needs and priorities of members; promote VCT especially among the family members of the PLHIV; build the belief that PLHIV can live long; reduce HIV and AIDS related death rates; promote the thinking of positive living among PLHIV (http://www.worldaidscampaign.org, Alula Pankhurst and others, 2008, Country Progress Report on HIV/AIDS Response, 2012, Kenso HG and Zemene M 2000, Alemu T 2002, Admassu A, 2000, Ayalew S, 1991, Ethiopian Journal of Health Development - Vol 17, 2003,).

The qualitative and quantitative data and the document review showed that the organization's interventions and services were related with its objectives and contributed to the realizations of the objectives of the organization. The organization has five main objectives. These are:-

1. Reduce vulnerability and mitigate the impacts of HIV and AIDS on PLHIVs and their families. The organization had fight against the impacts of HIV and AIDS on its members by creating job opportunities through group and individual IGAs, provision of HBC services, creating and raises the awareness levels of the members on positive living with the virus, providing awareness raising education, psycho-social support, providing palliative care for those who had no relatives and supporters, Provide social, emotional, psychological and material supports without discrimination especially for the poor. The services helped to provide funeral services for the dead PLHIV, reduce HIV and AIDS related discrimination and stigma, create venues for the PLHIV to assist each other like in time of death and sickness, contribute to the reduction of the prevalence of the virus by reducing new infections (according to the Ethiopian Sub-National Estimate the overall regional prevalence rate was lowered to 1.1% in 2013).

2. Reduce ART defaulter rate among ART attendant by 15 % at the end of 2015.

The organization did not directly provide the ART for the beneficiaries. But it has consulted the beneficiaries to use and adhere to the ART, use condom, about the importance of hygiene and sanitation, proper eating habits etc. Therefore, the services of the HBC providers of TBCS^{+} have helped the beneficiaries to adhere to the ART and prevent themselves from other STIs and OIDs.

3. Improve the nutritional and income status of PLHIV (mother support group) and OVC.

The finding of the study revealed that the organization is working towards realizing this objective. The organization provided nutritional support to increase the nutritional and health status of PLHIV. It involved women and OVC to get better diet and income by engaging them in urban gardening.

4. Strengthen the implementation capacity of the association members and its constituents.

The result of the study illustrated that the organization had strived for the protection of the rights of the members; helped the voiceless to be heard as a result of forming their own association; helped to build the trust, confidence, morale, motivation, inspiration, hopes etc of the members; developed the belief among members to take care for other negative people; create job opportunity for number of members and beneficiaries through group and individual IGAs, urban gardening agriculture, etc.

5. Mobilize required resource for the execution of planned activities of TBCS.

The organization widened its resources bases and increased its annual incomes. For example, prior to 2012 the organization only implemented one project financed by the Global Fund through NBGP^{+} but in 2014 the number of the projects reached five in 2011 it only administered the annual income of Birr 254,955.00 but in 2014 it is running Birr 1, 015984.69).

Nevertheless, the findings also depicted the presence of some gaps that need further interventions. These gaps included that some of the members were involved in Vocational Trainings and IGAs without their capacities and interests. Therefore, though they were provided with the trainings and the startup capital, these beneficiaries wasted the fund and remained dependent. The newly recruited HBC providers had not provided with capacity building training and it was difficult to except efficient services delivery without proper training. The income sources of the organization were limited and insufficient to address the growing and diversified needs and interests of the members. The other major challenges of TBCS^{+} were the inability of the organization to get land from Assosa Municipality for the organization's office construction and houses building for homeless members. In addition, the budget for referral support was insignificant and it could not cover the expenses incurred.

CHAPTER SIX

VI. CONCLUSSION AND RECOMMENDATION

6.1 Conclusion

Based on the findings of the study, the following conclusions can be inferred.

1. The main victims of the epidemic were the productive and reproductive age groups though the virus does not leave any age group of the community.
2. The greater number of the members and the service clients of TBCS^{+} are females and females are more vulnerable to the HIV and AIDS and victims of its socio-economic impacts than their male counter parts.
3. The finding of the study showed that HIV and AIDS have precipitated divorcees and widows.
4. The study revealed that the service clients of TBCS^{+} are PLHIVs with low educational status and income level. Thus, PLHIV with low economic status and educational background are more attracted to join PLHIV associations than PLHIV with better educational backgrounds and middle and higher economic status, though HIV does not spare any group of the community.
5. The services provided by TBCS^{+} have contributed in empowering the members and averting the spread of the HIV virus and the impacts of the epidemic.
6. The finding of the study depicted that, TBCS^{+} has provided the services since 2002, from the time of its establishment. The study revealed that the services of TBCS^{+} can be categorized in to eight- HBC services, emergency care and transportation cost, funeral related services, provision of non-medical kits (blankets& bed sheet),

provision of nutritional support (plump nut) to chronically ill and bed- ridden PLHIV, provision of pocket money and medical-kits to HBC service providers, economic strengthening/IGAs, and members' representation and rights protection.

7. The data illustrated that all the services of the organizations were relevant in empowering and reversing the impacts and prevalence of the epidemic, though the degree of the importance of the services varies from service to service. The participants of the study identified the provisions of HBC services, IGAs, and provision of non-medical kits as the three most essential services and the provisions of funeral related cost, emergency care and transport cost, and members' representation and rights protection as the three least essential services. Whereas the provisions of pocket money and medical kits for HBC service providers and the nutritional supports in between.
8. The findings of the study revealed that the provision of these services by TBCS^{+} have contributed in improving the health conditions and the socio-economic status of the members.
9. The services have helped to enhance the social relationships of the members among their fellow members and the wider community.
10. The services have helped to bring attitudinal changes among the members to the virus and promote positive living with HIV, improved their confidence and self-esteem.
11. The services have contributed to reduce mother- to -child transmission of the virus, AIDS related death, bed-ridden PLHIV patients, HIV related stigma and discrimination etc.

12. The services, areas of intervention and objectives of the organization are aligned with HIV policies, guidelines, strategies etc.
13. The organization has served as informative, venue of sharing sorrows, grieves, experiences, a brigade to assist and support one another among members, and voices for the PLHIV.
14. The organization is working towards the realization of its objectives and addressing the needs and priorities of the members, though the efforts need to further strengthen.
15. Though the organization has widened its resource bases, it could not fully satisfy the members' needs and demands as the size of members have been increasing from time to time with diversified needs and demands.
16. The organization has established good and workable relationships with the stakeholders, though supports of the stakeholders are expected to be strengthened and more coordinated.
17. The services of the organization contributed to develop the trust, confidence, morale, motivation, inspiration and hopes etc of the members to enhance their participation in their socio-economic affairs.

6.2 Recommendations

Based on the findings of the study, the following key actions are recommended for further improvement of the services of TBCS^{+}, enhancement of the empowerment of PLHIV and reverse the impacts and prevalence of the virus.

1. There is the need to attract PLHIV with better educational backgrounds and economic status to join the association, because these individuals help to consolidate and enhance

the efforts and the contributions of the PLHIV associations in empowering PLHIV and reversing the impacts and prevalence of the epidemic.

2. The economic strengthening activities/ Income Generating Activities (IGAs) schemes are very essential to empower PLHIV, reduce the impacts of HIV on PLHIV, reduce the prevalence of the virus and contribute for the overall development of the country. So, the IGA schemes have to be strengthened and given emphasis as well as the interest and capacity of the participants of the IGAs have to get due consideration. It is recommendable that each and every IGA scheme should take into consideration the interest, skills and capacity of the beneficiaries.
3. HIV and AIDS is the issue of all. So, each and every stakeholder needs to give due consideration to the issue and offer regular and concerted support to PLHIV associations.
4. As each and every entity has its own role in reducing the impacts and prevalence of the epidemic, the mainstreaming of HIV and AIDS need to be given due attention and the coordinating body (HAPCO) and the decision making organs (the executives) have to facilitate the mainstreaming process at each level (at regional, zonal and Woreda levels).
5. As HBC services need not only great care, devotion, honesty, diligence, trustworthiness, humility etc, but also theoretical and practical skills and knowledge, the newly recruited HBC service providers need to get capacity building trainings on provision of HBC services prior to starting the mission.
6. With the increase of the members' size and diversification of their needs and interests, so to meet and satisfy the priority needs of the members the organization need to widen its resource bases and the donors, the regional government bodies, private enterprises etc need to allocate additional resources. In addition, the organization needs to mobilize

resources from local sources by applying various forms of resource mobilization mechanisms like telethons, bazaars, exhibitions.

7. The beneficiaries of IGA schemes could be productive and effective partly when they become determinant and confidence enough that the schemes would help them to be productive and self reliant. So, there is the need to make high effort to raise the awareness, the confidence, motivation, trust of the participants on the IGA scheme.
8. The fact that the construction of its own office would help TBCS^{+} to save its limited finance and to use this resource for other purposes. So, it is commendable that the concerned government organ to grant land to the organization to construct its office.
9. Many of the members of the organization live in rented house and house rent is one of the sources of HIV and AIDS related stigma and discrimination. So, it is advisable that the concerned government organ to grant land for the construction of houses for homeless PLHIV and save them from house rent related socio-economic crises and suffrages.
10. It is advisable to increase the cost for funeral services.
11. As HIV prevention is the main vehicle to reduce the prevalence of the epidemic, there is the need to strengthen HIV prevention activities and make effort in schools, religious institutions, meeting places etc on making aware the public in general and the Most At Risks Persons (MARPs) in particular about the prevention of HIV and HIV and AIDS related issues.
12. It is true that group IGA is preferable and vital to get additional and unreserved supports from the government and other actors in the forms of trainings, loans, and technical assistances etc, as well as to coordinate the beneficiaries' efforts, resources, skills and knowledge etc, and to observe unified, solid and concrete changes among the

beneficiaries. So, the PLHIV associations and other concerned bodies like Cooperatives Formation and Promotion and Micro and Small Scale Enterprise Offices and their experts have to work hard to develop the interest, confidence, trust and motivation of the beneficiaries to develop positive attitude to group IGAs.

13. To promote the interest and confidence of the participants on the IGAs, it is advisable to arrange exposure visits and experience sharing venues to PLHIV and the concerned bodies to other regions those are more effective and productive in IGAs in general and group IGAs in particular.

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APPENDICES

Annex I

Verbal Consent Form for Participants of the Study/Informed Consent

Dear respondent,

Good morning/good afternoon. My name is Fantahun Melesse and I am studying Master of Social Work (MSW) at Indira Gandhi National Open University (IGNOU). For the partial fulfillment of the requirement for the Master Degree, I intend to study the "*contribution of PLHIV Associations in empowering PLHIV and reversing the impacts of HIV/ AIDS with particular emphasis to TBCS$^+$ of Assosa District in Benishangul Gumuz Regional State, Ethiopia"*.

This interview is designed to collect primary data from the beneficiaries, Board of Directors, and staff members of TBCS$^+$. Participation in this study is voluntary and everything you say will remain confidential. The responses given by the respondents will be primarily used for academic purposes. Thus, yours genuine and complete response is of paramount importance for the success of the study and to understand the contributions of the services of TBCS$^+$ in empowering the beneficiaries and reverse the impacts of the epidemic.

Your name will not be written on this form, and will never be used in connection with any of the information you provide. You may not answer any of the questions that you do not feel comfortable with, and you may end the interview at any time you want to cease. You may be contacted again if the researcher needs additional information. I would greatly appreciate your help in responding to the interview. The interview will take 30-40 minute.

Would you be willing to participate in the interview? 1. Agree ☐ 2. Disagree ☐

Thank You

Annex II

Interview Schedule for PLHIV (members/beneficiaries of TBCS^{+})

General Information

Respondent's code: _____

Time of the commencement of the interview: _____Ending Time: _____

Interviewer's name: _____

I. Questions on Socio-Demographic Characteristics of the Respondents

1. Age: _____

   1.18-30 ☐ 2.31-40 ☐ 3. 41-50 ☐ 4.51-60 ☐ 5. Above 60 ☐

2. Sex: _____

   1. Male ☐ 2. Female ☐

3. Marital Status _____

   1. Married ☐ 2. Single ☐

   3. Widowed ☐ 4. Divorced ☐

4. Your position in relation to the family you live with? _____

   1. Husband/family head ☐ 2. Lady of the house/ wife ☐

   3. Others ☐

5. Educational Status_____

   1. Illiterate ☐ 2. 1-8 Grades ☐

   3. 9-12 Grades ☐ 4. Certificate and above ☐

6. Occupation _____

7. Monthly income_____

1. Less than birr 500.00 ☐ 2. From birr 501.00 -1000.00 ☐

3. From1, 001.00 - 1,500.00 ☐ 4. Above birr 1,500.00 ☐

II. Questions Related with Empowerment Services Provided by TBCS+

1. What services did you get from TBCS+?

1. Home Based Care Services ☐
2. Provision of emergency care & transportation cost Pocket ☐
3. Provisions of funeral related costs ☐
4. Provision of Non-medical kits ☐
5. Nutritional support ☐
6. Provision of pocket money and medical-kits ☐
7. IGAs and capacity development trainings ☐
8. Members representation and rights protection ☐

2. For how long have you been getting the services from TBCS+?

1. < 3 years ☐ 2. 3-5 years ☐ 3. >5 years ☐

3. Do the service(s) contribute to bring changes in your or/and your family health conditions?

1. Yes ☐ 2. No. ☐ Please elaborate you response_____

4. Do these services contribute to bring change in your income or economic condition?

1. Yes ☐ 2. No. ☐ Please elaborate your response_____

5. Do these services bring change in your social relation with other people?

1. Yes ☐ 2. No. ☐ Please elaborate your response_____

6. Do these services bring change in your attitude towards HIV and AIDS or yourself?

1. Yes ☐ 2. No. ☐ Please elaborate your response_____

7. Do you think that your or/and your family current situation would be deteriorated, if you were not provided with such services by TBCS+?

1. Improved ☐ 2.worsened ☐ 3. No Change ☐ Please elaborate you the response_____

8. Do you think the services that have been provided by TBCS^{+} contributing in reversing the impacts and prevalence of HIV and AIDS?

1. Yes ☐ 2. No ☐ Please, elaborate your response) _____

9. What are the benefits of the services provided by TBCS^{+}? _____

10. What are the limitations of the services provided? _____

11. In your opinion, what are the most essential service (mention at least 3 services) and the least essential services provided by TBCS^{+} with the possible reasons? _____

12. Do you think TBCS^{+} has been addressing the needs and priorities of its members?

5. 1. Yes ☐ 2.No ☐ (Please, elaborate your response) _____

13. Do you think TBCS^{+} is realizing its objectives?

1. Yes ☐ 2.No. ☐ Please, elaborate your answer _____

14. Have you ever been satisfied with the services provided by TBCS^{+}?

1. Yes ☐ 2. No ☐ (Please state your answer) _____

15. In your opinion, are there any comments or recommendation that TBCS^{+} have to focus (area of focus, new intervention areas/services to be provided etc)? (If yes, please elaborate your answers) _____

_____

Thank You

Annex III

Interview Guide for Staff and Board Members of TBCS^{+}

Name and Position of the Interviewee _____

Time: _____

1. What are the services that have been provided by TBCS^{+} to the clients? _____
2. How far these services contributed to the empowerment of the beneficiaries and reversing the impacts of HIV and AIDS (Would you like state the contribution of each service separately)? _____
3. What are the benefits of these services? _____
4. What are the limitations of these services? _____
5. Do you think these services have been aligned with the HIV and AIDS policies, guidelines strategies etc ?(elaborate with possible reason)_____
6. How far does your organization attain its objectives?(elaborate with possible reason)___ _____
7. Do you think that TBSC^{+} meets the needs of its members?(elaborate with possible reason)_____
8. In your opinion, what are the three most and least essential services with the possible reasons_____
9. In your opinion, do members and beneficiaries satisfy with the services of your organization (Please, elaborate your answer)_____
10. How do you evaluate your organization relationship with the stakeholders? (Elaborate with possible reason)._____
11. Do you think that the different stakeholders are playing their role in a way they are expecting to do? If not why? Could you recommend what have to be done by the stakeholders? _____
12. Could you describe some of the major challenges you face in providing your services? _____

Thank You!

Annex IV

Focus Group Discussion for Selected Beneficiaries

Time: _____

Number of Participants: _____

1. What services have you been provided by $TBCS^{+?}$
2. How far these services contributed to bring change in your lives, health, attitude towards HIV/AIDS, reversing the impacts of HIV and AIDS (Would you like state the contribution of each service separately)?
3. What are the benefits of these services?
4. What are the limitations of these services?
5. Do you think that $TBSC^{+}$ meets the needs of its members/ addresses your need?(elaborate with possible reason)
6. Have you ever been satisfied with the services provided by TBC^{S+}?

RESEARCH PROPOSAL

PROJECT TITLE: EMPOWERMENT OF PEOPLE LIVING WITH HIV AND AIDS:

THE CASE OF TESFA BILICHITA CHARITABLE SOCIETY TO

PEOPLE LIVING WITH HIV

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTERS IN SOCIAL WORK (MSWP-001)

BY FANTAHUN MELESSE MERISSO

ENROLLMENT NO: ID1051106

SIGNATURE: _____

NAME OF THE STUDENT CENTER: ST. MARY UNIVERSITY, ADDIS ABABA, ETHIOPIA

PROJECT SUPERVISOR: MR. EPHRAIM MEBRATE

SUBMITTED TO: INDIRA GANDHI NATIONAL OPEN UNIVERSITY, SCHOOL OF SOCIAL WORK, NEW DELHI

ADDIS ABABA, ETHIOPIA

OCTOBER, 2014

PROFORMA FOR SUBMISSION OF MSW PROJECT PROPOSAL FOR APPROVAL FROM ACADAMEC COUNSELLOR AT STUDENT CENTER

Name of the Student: Fantahun Melesse Merisso

Enrolment Number: ID1051106

Date of Submission: 05 October 2014

Name of the Student Center: St. Mary University, Addis Ababa, Ethiopia

Name of the Guide: Mr. Ephraim Mebrate

Title of the project: Empowerment of People Living with HIV and AIDS: The case of Tesfa Bilichita Charitable Society to People Living with HIV

Signature of the student_____

Approved/ not approved

Signature: _____ Name and address of the student:

Name and Address of the Guide: Ephraim Mebrate Fantahun Melesse, Assosa, Ethiopia

Addis Ababa, Population Services International Date: 18 May 2015

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Acronyms

1. AIDS-Acquired Immuno Deficiency Syndrome
2. ART-antiretroviral therapy
3. BCC- Behavior Change Communication
4. BG-Benishangul Gumuz
5. BG HAPCO- Benishangul Gumuz HIV and AIDS Prevention and Control Office
6. BGDAN- Benishangul Gumuz Development Associations Network
7. BGRS- Benishangul Gumuz Regional State
8. DHS- Demographic and Health Survey
9. EBCA-Ethiopian Business Coalition on AIDS
10. EDHS- Ethiopian Demographic and Health Survey
11. FDRE- Federal Democratic Republic of Ethiopia
12. FGD- Focus Group Discussion
13. FHAPCO- Federal HIV and AIDS Prevention and Control Office
14. GIPLHIVs- Greater Involvement of Persons Living with HIV
15. GIPA -Greater Involvement of People with AIDS
16. HAPCO-HIV and AIDS Prevention and Control Office
17. HBC- Home Based Care
18. HIV- Human Immunodeficiency Virus
19. IEC- Information, Education and Communication
20. IGAs -Income Generation Activities
21. MDGs- Millennium Development Goals

22. NBGP+ -Network of BG HIV Positives' Charitable Society Consortium

23. NEP+- Network of Networks of HIV Positives in Ethiopia

24. OVC- Orphans and Vulnerable Children

25. PANE- Poverty Action Network in Ethiopia

26. PLHIV-People Living with HIV

27. PMTCT-Prevention of Mother -to -Child Transmission

28. $TBCS^{+}$- Tesfa Bilichita Charitable Society to PLHIV

29. UNAIDS-Joint United Nations Program on HIV and AIDS

30. GDP- Gross Domestic Product

31. UNDP-United Nations Development Program

32. US- The United States

33. USAID- United States Agency for International Development

34. VCT-Voluntary Counseling And Testing

35. WHO- World Health Organization

Definition of Terms

6. Regions-are the states that together form the Federal Democratic Republic of Ethiopia. Currently the FDRE consists of nine regional states and two City Administrations.
7. Zone-an administrative unit below Region and above Woredas. It consists of number of Woredas
8. Woreda-an administrative unit below a zone and above a Kebele. A Woreda is equivalent to a district and consists of a number of Kebeles.
9. Kebele- the lowest administrative unit in Ethiopia(village associations and urban neighbourhood associations)
10. Empowerment-to strengthen and improve the economic income and social relationship as well as attitude, outlook and confidence of the PLHIV and AIDS.

CHAPTER ONE

I.INTRODUCTION

1.1. **Background of the Study**

The emergence of HIV and AIDS epidemic is one of the biggest public health, psycho-social, economic challenges the world has ever seen in recent human history. In the last three decades HIV has spread rapidly and affected all sectors of society- young people and adults, men and women, and the rich and the poor (Country Progress Report on HIV/AIDS Response, 2012). HIV and AIDS create the most serious threats of global stability and progress through demolishing the human being particularly the productive and reproductive citizens who drive development. In Ethiopia, HIV/AIDS with poverty and drought is bringing a cripple effect on future prospects (Frehiwot, 2010).

The origin of this mysterious disease has puzzled every one ever since its recognition in early 1980s. Thereafter, HIV and AIDS have expanded in magnitudes and impacts and become one of the major challenges of health, life and development. According to USAID 2011 report cited in HIV and AIDS Mainstreaming Training Manual, May 2012, worldwide HIV and AIDS has been the cause of death for over 30 million people; about 34 million people live with the virus including 3.4 million children less than 15 years. In 2011 an estimated 2.5 million people were newly infected with HIV of which 330,000 were under the age of 15. Every day nearly 7,000 people contact HIV-nearly 300 every hour. In the same year 1.7 million people died of AIDS; 230,000 of them were under the age of 15.Since the beginning of the epidemic, more than 60 million people have contacted HIV and nearly 30 million have died of HIV-related causes(UNAIDS World AIDS Day Report 2012;UNAIDS Fact Sheet 2012 cited by Ermiyas,2013). As the MDG 2011 report, globally, nearly 23 per cent of all PLHIV are under the

age of 25, and young people (aged15 to 24) account for 41 per cent of new infections. Sub-Saharan Africa remains the most heavily affected region, accounting for 69 per cent of new HIV infections, 68 per cent of PLHIV and 72 per cent of AIDS deaths (UN 2011 MDG Report).

Ethiopia as the Sub-Saharan country and the second largest populous (with about 80 million people) state in Africa, it is among the countries most affected by epidemic. The existence of HIV in Ethiopia recognized in1980s with the first two AIDS cases reported in 1986(Lester FT and others 1988, cited in GAP Report on AIDS, 2012). Since then, the epidemic has rapidly spread throughout the country. With an estimated adult prevalence of 1.5%, Ethiopia has about 800,000 PLHIV including about 182, 200 children aged 0-14 years; and about 1 million AIDS orphans (Country Progress Report on HIV/AIDS Response 2012, the DHS 2011 data).

Benishangul Gumuz Regional State (BGRS) is one of the nine regional states in Ethiopia which is highly affected by HIV and AIDS. In BGRS the estimated adult prevalence rate is 1.2 %, and the annual death rate is 705 persons (Ethiopia Sub-National Estimates of June 2012).

The struggle against this devastative episode needs the concerted efforts of every actor at every level (2012 TBCS^{+} Annual Report).In the combat of HIV and AIDS, reversing its adverse effects and empowering the People Living with HIV (PLHIV), the PLHIV and their associations have valuable and significant contributions. But there is a gap in assessing, appreciating or proposing corrective recommendations concerning the contributions of the PLHIV associations in empowering PLHIV and reversing the impacts of HIV and AIDS. Taking all these facts into accounts and gaps in the wide arrays of literatures, this study aims to assess the contribution of PLHIV associations in empowering PLHIV and reversing the adverse impacts of HIV and AIDS with particular emphasis on Tesfa Bilichita Charitable Society to PLHIV (TBCS^{+}).

1.2. Statement of the problem

The impacts of the pandemic are felt in all areas of life. HIV and ADIS is not only a killer disease likes other diseases known to human beings but also it kills a person and affects the development endeavor of a country and it becomes a source for the violation of human rights. A paper produced by Ethiopian Business Coalition on AIDS (EBCA) in September 2009 on HIV/AIDS and Human Rights clearly reveals that how HIV and AIDS differs from other major killing diseases and antagonizes the values and principles of human rights, defame human dignity as "…What is the difference about HIV/AIDS? The impact is not only the physical health of individuals but also their social identity and condition; the stigma and discrimination surrounding HIV/AIDS can be as destructive as the disease itself; lack of recognition of human rights; and loss of dignity for people living with HIV or AIDS".

HIV and AIDS is posing formidable challenge to the development of all sectors as illnesses and deaths from AIDS reduce productivity of their labor forces. Responding effectively to the behavioral, psycho-social, cultural, and economic factors that make individuals and communities vulnerable to HIV infection and mitigating the associated crises of AIDS require organized and concerted efforts from all actors (FHAPCO Road Map, 2010). Unless strong action is taken, the pandemic will continue to threaten the delivery of sustainable social services and the attainment of the MDG (Frehiwot, 2010).

Significant empowerment initiatives have been provided by PLHIV organizations to PLHIV, their families and OVC through education and VCT services; care and treatment, ART provision, provision of PMTCT services (Country Progress Report on HIV/AIDS Response, 2012). The meaningful involvement of PLHIV and affected communities makes a powerful contribution to the HIV response by empowering PLHIV or affected by HIV to draw on their experiences to

reduce stigma and discrimination and increase the effectiveness and appropriateness of HIV programs. PLHIV participation in all aspects of HIV programs is a pre-requisite to best meet

In his speech at the National HIV Summit (2009), Mr. Tigabe Asres, Executive Director of the Network of Networks of HIV Positives in Ethiopia (NEP+), clearly shows the indispensability of the GIPA principles, the contributions of PLHIV and PLHIV Associations in combating HIV and AIDS and reversing its effects as follows;

> "Individual PLHIVs and their associations have been at the forefront of the prevention effort particularly at the initial stage of the national response. This is the role they can continue to play if they are provided with the necessary support. Positive prevention is a strategy that has a major role to play in averting re-infection among PLHIV, between discordant couple and also reducing transmission to the general population. Thus, there is an urgent need to scale up the positive prevention activities initiated and involve the PLHIV community as a major stakeholder in the planning and delivery of the services both the health facility and community level."

Currently there are numbers of associations of PLHIV working all over Ethiopia including BGRS. Research papers and findings began to be produced in relation to the PLHIV Associations and Networks in particular and the issues related with HIV and AIDS in general. The associations of PLHIV are providing social support and encouragement; hope and a safe haven for sharing of experiences, seeking refuge from discrimination, finding moral support and encouragement, as well as obtaining financial assistance, particularly for the poorest who are the main participants of such associations(Alula Pankhurst and others, 2008). Annania(2000),provides a background to the establishment and development of PLHIV associations in Addis Ababa, the MA theses of Sebsib(2002) and Mekete(2005) provide evidence of growing support that associations of PLHIV from Bahir Dar and Nazreth respectively(cited in Alula et.al 2008). Getnet (2008) in his MA thesis tried to assess the knowledge, attitude and practices of rural women in relation to

HIV/AIDS with particular emphasis on Wad- Eyesus Woreda of Amhara Region. Frehiwot(2010) assesses the role of education sector in preventing and mitigating the impact of HIV/AIDS on development with particular emphasis in Ethiopia. Ermias Bekele (2013) studied the provision of transaction-prevention and care services for Most At Risk Population by Integrated Services for Prevention and Support Organization and Pro Pride. However, this researcher believes that the studies on contributions of the associations of PLHIV in empowering the PLHIV and reversing the impacts of HIV and AIDS are inadequate and that of BGRS is absent. Thus, this paper intends to assess how far the associations of PLHIV contribute in empowering PLHIV and reversing the impacts of HIV and AIDS with particular emphasis on Tesfa Bilichita to PLHIV ($TBCS^{+}$).

1.3. OBJECTIVES OF THE STUDY

The general objective of study is to assess the contribution of Tesfa Bilichita Charitable Society to PLHIV in empowering PLHIV and reversing the impacts and prevalence of HIV and AIDS.

This study specifically intends to:-

1. Assess the contributions of the services of $TBCS^{+}$ in empowering the PLHIV and reversing the impacts and prevalence of HIV and AIDS.

2. Assess the alignment of the interventions of $TBCS^{+}$ with the HIV and AIDS policies.

3. Review how far $TBCS^{+}$ meets its objectives.

1.4. Significance of the Study

A number of studies have been conducted on HIV and AIDS related topics and issues. These studies mainly focus on HIV and AIDS related discrimination and stigma; impacts of HIV and

AIDS; HIV and AIDS counseling and testing; etc. Nevertheless, the assessment of the contribution of PLHIV Associations in empowering PLHIV and reversing the effects of HIV and AIDS is overlooked. So, there is a need to conduct practical research that shows the contribution of PLHIV associations. The researcher believes this study will help to reveal the services that have been provided by the associations of PLHIV and the contributions of the services in empowering the beneficiaries and reversing the impacts of HIV and AIDS; to show how far associations' intervention align with the HIV and AIDS policies with special emphasis of $TBCS^{+}$

It is also important to propose recommendations for the future intervention of $TBCS^{+}$ if there is deviation from its objectives, the needs of the target groups and the HIV and AIDS policies and strategies. It may also serve other associations of PLHIV to evaluate their interventions in light of the findings and recommendations of this paper. In addition, it will pave the way for other researchers to further investigate the contributions of the associations of PLHIV in empowering PLHIV and reversing the impacts of HIV and AIDS. Moreover, this study may initiate the concerned bodies to give due attention to PLHIV associations and support their cases and efforts.

1.5. Ethical consideration

Informed consent is the major ethical issue in conducting Social Work Research. In this regard, the researcher will attempt to get the informed verbal consent from each of the study subject. Each participant of the study will be informed the objective of the study and his/her right to voluntarily participate in the interview or not. As they will not get any remuneration for their participation in the interview, the researcher will impart the importance of the study and get their voluntarily participation without expecting any payments. Each participant will be informed that his/her answer would remain anonymous, confidential and only to be used for this study purpose.

CHAPTER TWO

RESEARCH DESIGN AND METHOD

2.1. Research Design

The study will use descriptive research design and qualitative research method. The researcher intends to employ the descriptive research design as it helps to elicit information concerning the contribution of associations of PLHIV in empowering their members and reversing the adverse impacts of HIV and AIDS. Descriptive research design helps to explain the existing conditions or relationships, prevailing practices, current beliefs, point of views or attitudes, processes that are going on and their effects and the developing trends. Qualitative research approach helps to study social phenomenon within its natural context. It also enables to have in-depth understanding of a few numbers of cases rather than a general understanding of many cases or people (Grinnel, 2001 cited in Etabezahu, 2013). Qualitative research is best suited for a topic, which is sensitive and emotional like HIV and AIDS that require empathy and understanding (Ermias, 2013). According to Maxwell 2005, the qualitative method helps to understand the meaning of situations, event, experiences, and actions of participants.

2.2. Study Area

The study area of this project proposal is Assosa District of Benishangul Gumuz Regional State (BGRS), in Ethiopia. The BGRS is one of the nine regional states and two city administrations that constitute the Federal Democratic Republic of Ethiopia (FDRE). The BGRS is located in the western part of Ethiopia sharing borders with Amhara Regional state to the north and northeast, with Oromiya Regional State to the southeast and south, with South Sudan, and the Sudan to the west. BGRS is divided into 3 administrative zones as Assosa, Kamashi and Metekel; 20 Districts

(woredas) of which one is Special District, 1 city administration and 475 kebeles. Assosa is the capital city of the BGRS, Assosa Zone and Assosa Woreda and located 661 km far away from Addis Ababa in the west. The region has an estimated land area of 50,698.68 Sq. km.

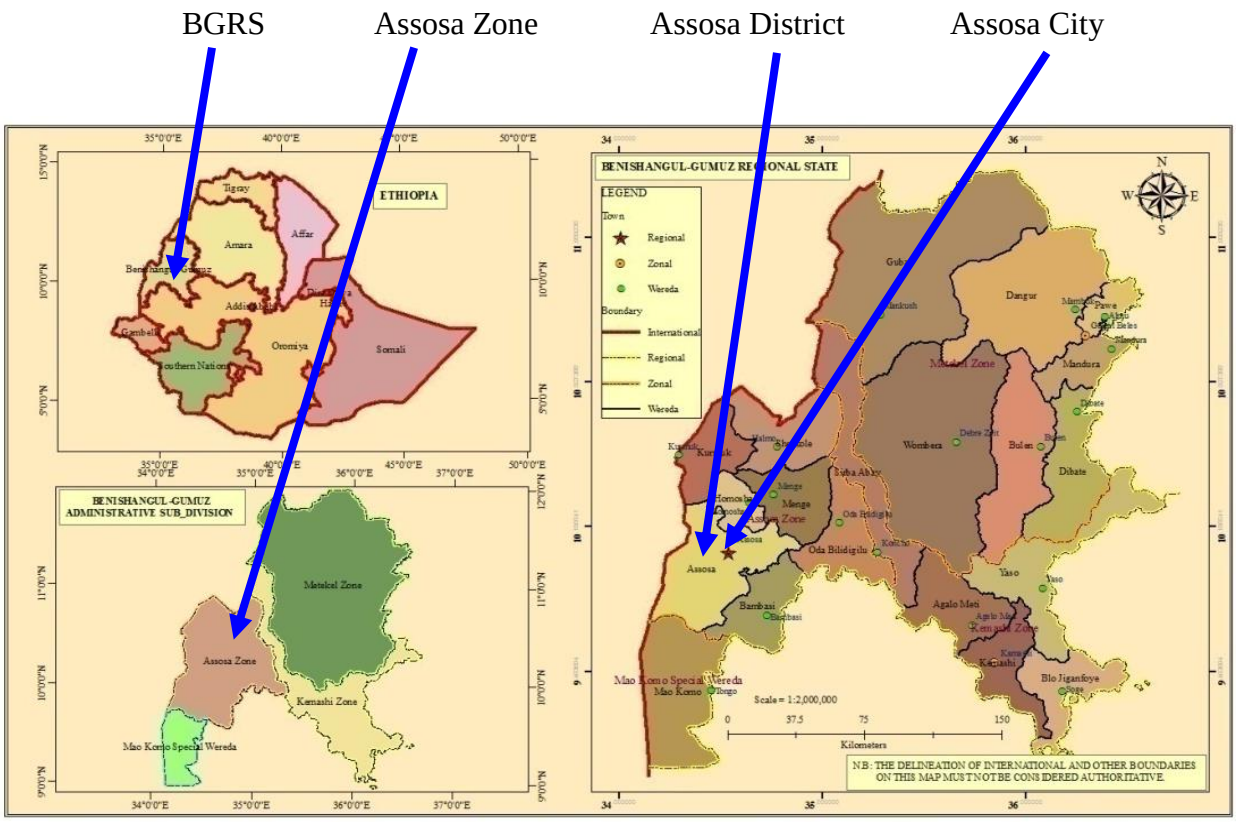

Fig.1.The Map of BGRS, Assosa Zone, Assosa Woreda and Assosa City

The mean annual temperature of BGRS is found between 23-25^{0}c in the low land and 10-15^{0}c in the high land. February to May is the hottest months while October to January is the coldest months. BGRS is a zone with great physiographic diversity. There are a great altitudinal differences between the highest and the lowest places. The lowest place is in the Blue Nile, which crosses the Ethio-Sudan border (443masl). Whereas, the highest peak in the region is Belaya plateau in Dangur woreda (2,857masl).

The BGRS is inhabited by five indigenous nations, nationalities and peoples, namely the Berta, Gumuz, Shinasha, Mao and Komo. In addition, other nations, nationalities and peoples including Amhara, Oromo, Agew, Tigrie, and Garage etc are also residing in the region (CSA, 2011). According to the 2012 projection, the overwhelming majority of the populations (83.4%) live in rural areas and the remaining 16.6% in urban centers. The population size of the region, as of July 2012 estimation was 982,004 (499,004/50.8% males and 483,000/49.2%) females.

The target district where, TBCS^{+} is operating is called Assosa. It is one of the 20 districts of BGRS. It is located in Assosa Zone. Assosa District has 74 rural kebeles and 4 urban kebeles of Assosa City. The rural areas cover the area of 2,917.67 sq. km and Assosa City has the area of14.58 sq.km. According to July 2012 estimation the Woreda had the total population of 133,757(68,052 males and 65,705 females) and it stands first in terms of population (it accounts 13.62 per cent the population of BGRS). From this population 37,365(19,232 males and 18,133 females) live in urban areas and 96,392(48,820 males and 47,572 females) in rural kebeles.

TBCS^{+} is a PLHIV association. It is established to serve the PLHIV and curb the impacts of HIV and AIDS. It is working in the 74 rural Kebeles of Assosa Woreda and 4 kebeles of Assosa City.

2.3 Study Population

The study population of this paper will be the adult members or the 455 (188 or 42.32% males and 267 or 58.68% females) members of TBCS^{+}. TBCS^{+} had 455(188 males and 267 females) adult and 79 (46 males and 33 females) children members. Totally, the association consisted of 534(455 adult and 79 children, 234 males and 300 females') members. Of which, 35 (19 males and 16 females) were elders and 5(2 males and 3 females) were Person Living with Disability.

2.4 Sampling Technique/method

Non-probability sampling technique will be used to identify participants of the study. Interview and FGD will be used as the main tool for data collection**.** The researcher will employ the purposive sampling technique of non-probability sampling method. The purposive sampling technique is preferred due to its cost effectiveness and avoidance of time wastage. It is the most common sampling technique where participants of the study are selected according to pre-set criteria relevant to a particular research questions (Natasha et.al. 2005:6 in Ermias, 2013). To validate that informants meet the right criteria for the study, the researcher will select the participants based on age (18 years old and above), being beneficiary of TBCS^{+}, consent to participate in the interview (for the beneficiaries); the criteria for board members will be voluntary to participate in the study; and the criteria for the staff members will be his/her direct involvement in the service provision for the clients and voluntary to participate. Generally, the respondents will be selected on the basis of the purposes of the study and the inclusion criteria.

2.5 Sampling Size

The sample sizes/ the subjects of the study will be 46 individuals including PLHIV beneficiaries, Board members and staff members. The samples will include three groups of informants: 40 PLHIV members (beneficiaries) of TBCS+; 3 board members; and 3 project staff members. The researcher may also conduct field observations and documentary review relevant to the study.

2.6 Inclusion/Exclusion Criteria

The researcher will select 46 respondents who satisfied the purpose and the inclusion criteria of the study. The inclusion criteria include age (18 and above), willingness to participate in the

interviews, be beneficiary of TBCS^{+}, being members of the board of directors or an employee of the organization. The beneficiaries those who are not PLHIV and under 18 will be excluded.

2.7 Data Collection Tools and Procedures

Since social reality in general and social work research in particular are complex and multi-faceted activity, a single data collecting tool may not be adequate and suffice to gather the desired and relevant information. Thus, this study will use various data collection tools so as to attain the objectives of the study. So, the researcher proposes interview schedule, interview guide, focus group discussion (FGD), field observations and review of secondary data.

The main tool of data collection shall be the interview schedule which shall be used to collect data from the 40 members of TBCS^{+}. The interview questions will comprise both closed and open ended questions. The interview schedule shall be pre-tested. Then the interview schedule would be standardized, finalized and employed to the 40 beneficiaries (individual interview). The interview guide/ the semi structure interview will be administered to the 3 boards, and 3 staff members. The researcher would also conduct FGD with 8 to 10 selected beneficiaries and review and analysis of available documents (reports, plans, publications etc). Moreover, there will be field observation of the services those have been provided to the beneficiaries. The interview will be conducted in two -ways of communication form (both give and receive information). In addition, the researcher will observe the feeling and emotion of the respondents.

2.8. DATA ANALYSIS

The collected data shall be scrutinized, verified, edited and arranged serially. Following the completion of the individual in-depth interview through proving and semi-structured interviews and FGD, the researcher will employ categorization and re-categorization of relevant themes in the study. By doing so, the researcher will use the thematic analysis of qualitative data. The relevant data gathered from the secondary sources or documents would be analyzed and interpreted systematically. The review of these documents may help to identify the gaps, the areas of overlap, and the contradictions and substantiate the gaps in the study.

2.9. CHAPTER PLAN

This paper will consist of six chapters. These include:

1. The first chapter shall be an introductory part of the study.

2. The second chapter states the review of related literatures.

3. The third chapter shall deal with the study design, and method and the study area.

4. The fourth chapter will refer to analysis and interpretation of data.

5. The fifth chapter shall state the main findings,

6. The sixth chapter shall discuss conclusion and possible recommendations.

The appendixes shall include informed consent, the interview schedule, interview guide, the FGD questions and references/bibliographies.

2.10. REPORT WRITING

Every research is finalized by presenting its findings in the form of a report. The reporting of the results of a research study depends on purpose. So, since this study is a thesis for the partial fulfillment of Master of Social Work, the results of the study would be submitted to Indira Gandhi National Open University School of Social Work in the form of report by following the conventional research reporting formats and in the sequential and logical manners. The research report will have three broad parts (the preliminary, the main body and the end) and sub- sections.

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APPENDICES

Annex I

Verbal Consent Form for Participants of the Study/Informed Consent

Dear respondent,

Good morning/good afternoon. My name is Fantahun Melesse and I am studying Master of Social Work (MSW) at Indira Gandhi National Open University (IGNOU). For the partial fulfillment of the requirement for the Master Degree, I intend to study the "*contribution of PLHIV Associations in empowering PLHIV and reversing the impacts of HIV/ AIDS with particular emphasis to TBCS*$^{+}$ *of Assosa District in Benishangul Gumuz Regional State, Ethiopia"*.

This interview is designed to collect primary data from the beneficiaries, Board of Directors, and staff members of TBCS^{+}. Participation in this study is voluntary and everything you say will remain confidential. The responses given by the respondents will be primarily used for academic purposes. Thus, yours genuine and complete response is of paramount importance for the success of the study and to understand the contributions of the services of TBCS^{+} in empowering the beneficiaries and reverse the impacts of the epidemic.

Your name will not be written on this form, and will never be used in connection with any of the information you provide. You may not answer any of the questions that you do not feel comfortable with, and you may end the interview at any time you want to cease. You may be contacted again if the researcher needs additional information. I would greatly appreciate your help in responding to the interview. The interview will take 30-40 minute.

Would you be willing to participate in the interview? 1. Agree ☐ 2. Disagree ☐

Thank You

Annex –II

Interview Schedule for PLHIV (members/beneficiaries of TBCS^{+})

General Information

Respondent's code: _____

Time of the commencement of the interview: _____Ending Time: _____

Interviewer's name: _____

III. Questions on Socio-Demographic Characteristics of the Respondents

4. Age: _____

1.18-30 ☐ 2.31-40 ☐ 3. 41-50 ☐ 4.51-60 ☐ 5. Above 60 ☐

5. Sex: _____

9. Male ☐ 2. Female ☐

6. Marital Status _____

1. Married ☐ 2. Single ☐

3. Widowed ☐ 4. Divorced ☐

4. Your position in relation to the family you live with? _____

1. Husband/family head ☐ 2. Lady of the house/ wife ☐

3. Others ☐

5. Educational Status_____

1. Illiterate ☐ 2. 1-8 Grades ☐

3. 9-12 Grades ☐ 4. Certificate and above ☐

6. Occupation _____

7. Monthly income_____

1. Less than birr 500.00 ☐ 2. From birr 501.00 -1000.00 ☐

3. From1, 001.00 - 1,500.00 ☐ 4. Above birr 1,500.00 ☐

IV. Questions Related with Empowerment Services Provided by TBCS+

1. What services did you get from TBCS+?

1. Home Based Care Services ☐

10. Provision of emergency care & transportation cost Pocket ☐

11. Provisions of funeral related costs ☐

12. Provision of Non-medical kits ☐

13. Nutritional support ☐

14. Provision of pocket money and medical-kits ☐

15. IGAs and capacity development trainings ☐

16. Members representation and rights protection ☐

2. For how long have you been getting the services from TBCS+?

1. < 3 years ☐ 2. 3-5 years ☐ 3. >5 years ☐

3. Do the service(s) contribute to bring changes in your or/and your family health conditions?

1. Yes ☐ 2. No. ☐ Please elaborate you response_____

4. Do these services contribute to bring change in your income or economic condition?

1. Yes ☐ 2. No. ☐ Please elaborate your response_____

5. Do these services bring change in your social relation with other people?

1. Yes ☐ 2. No. ☐ Please elaborate your response_____

6. Do these services bring change in your attitude towards HIV and AIDS or yourself?

1. Yes ☐ 2. No. ☐ Please elaborate your response_____

7. Do you think that your or/and your family current situation would be deteriorated, if you were not provided with such services by TBCS+?

1. Improved ☐ 2.worsened ☐ 3. No Change ☐ Please elaborate you the response_____

8. Do you think the services that have been provided by TBCS^{+} contributing in reversing the impacts and prevalence of HIV and AIDS?

1. Yes ☐ 2. No ☐ Please, elaborate your response) _____

9. What are the benefits of the services provided by TBCS^{+}? _____

10. What are the limitations of the services provided? _____

11. In your opinion, what are the most essential service (mention at least 3 services) and the least essential services provided by TBCS^{+} with the possible reasons? _____

12. Do you think TBCS^{+} has been addressing the needs and priorities of its members?

7. 1. Yes ☐ 2.No ☐ (Please, elaborate your response) _____

13. Do you think TBCS^{+} is realizing its objectives?

2. Yes ☐ 2.No. ☐ Please, elaborate your answer _____

14. Have you ever been satisfied with the services provided by TBCS^{+}?

1. Yes ☐ 2. No ☐ (Please state your answer) _____

15. In your opinion, are there any comments or recommendation that TBCS^{+} have to focus (area of focus, new intervention areas/services to be provided etc)? (If yes, please elaborate your answers) _____

_____

Thank You

Annex III

Interview Guide for Staff and Board Members of TBCS^{+}

Name and Position of the Interviewee _____

Time: _____

13. What are the services that have been provided by TBCS^{+} to the clients? _____
14. How far these services contributed to the empowerment of the beneficiaries and reversing the impacts of HIV and AIDS (Would you like state the contribution of each service separately)? _____
15. What are the benefits of these services? _____
16. What are the limitations of these services? _____
17. Do you think these services have been aligned with the HIV and AIDS policies, guidelines strategies etc ?(elaborate with possible reason)_____
18. How far does your organization attain its objectives?(elaborate with possible reason)___ _____
19. Do you think that TBSC^{+} meets the needs of its members?(elaborate with possible reason)_____
20. In your opinion, what are the three most and least essential services with the possible reasons_____
21. In your opinion, do members and beneficiaries satisfy with the services of your organization (Please, elaborate your answer)_____
22. How do you evaluate your organization relationship with the stakeholders? (Elaborate with possible reason)._____
23. Do you think that the different stakeholders are playing their role in a way they are expecting to do? If not why? Could you recommend what have to be done by the stakeholders? _____
24. Could you describe some of the major challenges you face in providing your services? _____

Thank You!

Annex IV

Focus Group Discussion for Selected Beneficiaries

Time: _____

Number of Participants: _____

7. What services have you been provided by $TBCS^{+?}$
8. How far these services contributed to bring change in your lives, health, attitude towards HIV/AIDS, reversing the impacts of HIV and AIDS (Would you like state the contribution of each service separately)?
9. What are the benefits of these services?
10. What are the limitations of these services?
11. Do you think that $TBSC^{+}$ meets the needs of its members/ addresses your need?(elaborate with possible reason)
12. Have you ever been satisfied with the services provided by TBC^{S+}?

Thank You