Assessment on the Home based Care and Support Programme for Infected and Affected People with HIV/AIDS at Mekdem Ethiopia National Association in Addis Ababa, Ethiopia

MSW Dissertation Research Project Report
(MSWP-01)

Yared Tesfaye Wolde
Enrollment No. ID 1115141

Indira Gandhi National Open University
School of Social Work

May 2015
Addis Ababa, Ethiopia

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Project supervisor:
Sebsib Belay:

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DECLARATION

I hereby declare that the dissertation entitled ASSESSMENT ON THE HOME BASED CARE AND SUPPORT PROGRAMME FOR THE INFECTED AND AFFECTED PEOPLE WITH HIV/AIDS AT MEKDIM ETHIOPIA NATIONAL ASSOSIATION IN ADDIS ABABA ETHIOPIA submitted by me for the 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 program 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.

Addis Ababa

May, 2015

Signature:

Enrolment No:ID1115141

Name : Yared Tesfaye Wolde

Email: secretad99@yahoo.com

CERTIFICATE

This is to certify that Mr. Yared Tesfaye Wolde student of MSW from Indira Gandhi National Open University New Delhi was working under my supervision and guidance for his/her Project Work for the Course **MSWP-001.** His/her Project Work entitled ***ASSESSMENT ON THE HOME BASED CARE AND SUPPORT PROGRAMME FOR THE INFECTED AND AFFECTED PEOPLE WITH HIV/AIDS AT MEKDIM ETHIOPIA NATIONAL ASSOSIATION IN ADDIS ABABA ETHIOPIA***

Which he/she is submitting, is his genuine and original work.

Place: _____ Signature _____

Date: _____ Name _____

Address of the Supervisor _____

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Phone No. : _____

TABLE OF CONTENTS

CONTENTS PAGE NO.

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ABRIVATOINS AND ACRONYMS

AIDS	Acquired Immuno Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral Vaccination
CBOs	Community-Based Organizations
CHW	Community Health Worker
FBOs	Faith-Based Organizations
GIPA	Greater Involvement of People living with HIV/AIDS
HAPCO	HIV/AIDS Prevention and Control Office
HBCS	Home-Based Care and Support
HIV	Human Immunodeficiency Virus
IBCS	Institution-Based Care and Support
KOOWs	Kebele-Oriented Outreach Workers
NACP	National AIDS/STDs Control Programme
NASW	National Association of Social Workers
NGOs	Non-Governmental Organizations
PLH	People Living With the HIV/AIDS
TB	Tuberculosis
UNDP	United Nations
UNAIDS	United Nations Joint AIDS Programme
WHO	World Health Organization

LIST OF TABLES AND FIGURES

LIST OF MAPS

ABSTRACT

HIVAIDS is one of the global epidemics that has been affecting almost all countries of the world at varying magnitude and scope. The tragedy is much more felt on poor countries of Africa, Asia and South America. Millions of people have lost their lives to the HIVAIDS, millions of children lost their parents and became orphaned, the proportion of elders are today helpless and suffering from loneliness. In Ethiopia is no different and the tragedy holds true as well. However, there are several initiatives to contain the spread of the killer virus globally such as the WHO,UNAIDS, nationally such as HAPCO and locally through various NGOs . Among those NGOs, in Ethiopia Mekdim National Association (MENA) is the one that engaged in preventing and controlling the various through the new innovative approach called Home – Based Care and Support. The HBCS intervention method is undertaken through providing patients with medical, psychological and economic support at their homestead. The purpose of this particular study, therefore has attempted to make an overview on MENA's the activities involving the provision of care and support to patients in two project sites located in Arada and Gulele Sub-Cities in the city of Addis Ababa , Ethiopia. The study is based on the quantitative approach of research undertaking so that primary data were collected from the agreed sample population of the each project sites. Information gathered were analyzed and interpreted to make the study analytical and rational for the readership. There three set of respondents that contributed their accounts for the success of the study. That are 75 patients that are directly getting the HBCS from MENA, 7 Caregivers that are directly engaged in providing patients of clients with medical, psychological and socio-economic support and a project coordinator who directly supervises the day-to-day activities of MENA's HBCS process. In due course of the study, important findings are systematically formulated and logically presented based on the facts collected from the target groups of respondents. Equally important, logical conclusion has been made and some recommendations were suggested to take corrective measures on limitations of MENA's HBCS in particular and to expand the practice of HBCS to other parts of Ethiopia in general. The advantages of HBCS's to poor countries to Ethiopia, has been given a series attention on the last part of the study, where there exists an incompatible demand of patients and provision the necessary medical care support package. There it was also attempted to share the experiences of developing countries so that one can assume that such an intervention method is useful both for poor countries having financial difficulties to address public health one side and to poor patients in exempting them from medical and logistic costs.

Key Words: ***Caregivers, Patients, Counseling, Socioeconomic support, HBCS,***

CHAPTER ONE: INTRODUCTION

1.1 Background of the Problem

HIV/AIDS in one of the powerful killer epidemics of our times. Currently, since the start of the pandemic, some thirty years ago, our world has now become a home for about 35 million people living with HIV(UNAIDS,2014).However, the engulfing infection at a global scale has been on the rise and unabated from the past . In response, there has been unilateral and coordinated effort exerted both by individual countries and the international level. The continued global effort has now resulted in the sharp decline in terms of infection and transmission of the virus. According to the MGDs 2011 Report, currently, the number of new HIV (Human Immunodeficiency Virus) infections is 1.2 to 1.4 per 100 adults(aged 15 to 49)(UNAIDS 2013). . Southern Africa and Central Africa, the two regions with the highest incidence, saw sharp declines of 48 per cent and 54 per cent, respectively. It should be noted that, still, there were an estimated 2.3 million cases of people of all ages newly infected and 1.6 million deaths from AIDS-related causes. Sub-Saharan Africa was the region where 70 per cent—1.6 million cases—of the estimated number of new infections in 2012 occurred (UNDP 2014).

Ethiopia is no different from this global pandemic with its prevalence and alarming spread which evolved from two cases in 1986, is spreading alarmingly and infected 1,475,000 (658,000 males and 817,000 females) people in the country (Ministry of Health , 2004 fact sheet). Despite the encouraging improvements in the process of combating the crisis of the epidemic, studies show that the challenge still persists and more to be done in the race to achieve the desired results. For example, the 2014 Human Development Report has put Ethiopia's prevalence rate at 47.2 percent

HIV/AIDS is more pronounced in adult age groups (15-49) According to the UNAIDS (2013) the highest number of HIV infected segment of the Ethiopian population (540,000 - 670,000) are in this age group. As this age group of persons are the economically active, the social and economic basis of the family and the society their death leaves the country with long lasting development problems. One of the worst impacts is leaving many

children without parents (MOH, 1998). Before AIDS, about 2% of all children in developing countries were orphans but in 15 years from the first identification of AIDS the number skyrocketed to 7% - 11% in African countries (Microsoft Encarta) 15–17% (Deininger, et al., 2003). And ninety five per cent of children orphaned by the pandemic live in this continent (Save the Children UK,2001)

In order to contain the spread of HIV/AIDS there have been several conventional and globally accepted practices aimed at mitigating the spread of HIVAIDS such as ART provision, condom distribution, voluntary testing and counseling. The HBCS meaning Home-Based Care and Support is another approach to the same effort.

According to the Joint United Nations Program on HIV/AIDS Report , Ethiopia is one of the seven countries – together with Botswana, Ghana, Malawi, Namibia, South Africa, and Zambia – showing a rapid decline by 50% or more. The report has emphases the role of HBCS to have played an indispensable role for the benefit of the majority of the population- in rural parts of those countries (UNAIDS 2015).

The HBCS is one of the recently employed preventive mechanisms as an alternative approach to that of the conventional approach called the Institution-Based Care and Support (IBCS). nowadays its popularity is growing and many poor countries are practicing in effort to contain both the spread and prevalence of the killer virus in many developing countries, notably in many poor African countries such as Uganda ,Botswana, South Africa and Zimbabwe (HIV/AIDS Country Progress Report, Uganda; 2013). This approach is preferred by many poor countries for its range of advantages in terms economic and convenience. Firstly, it enables the poor that cannot afford for treatment and transportation long distance to reach health institutions. Secondly, it curbs the burden on health institutions with limited financial, material and human resources. The major features of the HBCS are that it involves little costly activities but largely human interaction between the care and support providers and the HIVAIDS patients and training at a community level.

From the facts above one can easily understand that that HBCS is an approach the most preferable and convenient for providing the necessary care support to patients' homestead at one hand and the burden of costs for transportation, treatment, accommodation, etc. Where health institutions are largely located in urban areas on the other. The other twin advantage of the HBCS is also for its contribution in minimizing the bourdons on health institutions, where the available resources are meager (HAPCO)**.**

So far, there are several mechanisms employed to deal with the effects of HIVAIDS in many countries. Institution –based treatment, preventive education and training, ARV drug distribution etc are the most common approaches practice for many years, however, the Home-Based Care and Support, has been devised as an effective and economic alternative mechanism. Since its introduction in 2000, many countries have adopted it in their national policies, strategies to combat the pandemic.

According to the 2012/2013 Annual Performance Report by the MoH, in Ethiopia, in fact there are positive changes in terms of an increase the number of PLWHA over the last nine years with combination of sustained prevention and increased ART coverage. As a result, the number of new infections has dropped. For example, between 2004 and 2005EC for PLWHA ever enrolled in HIV/AIDS care has increased from about 667,000 to 744,000 that was only not more than 190 some nine years back respectively. The same is true for the number of patients that are actually getting care and support under the HBCS. The Report indicated under the same period from close to 275,000 to 309,000.

The need to conduct this particular study on the topic under discussion is initiated as part of making empirical contribution to the debate over combating the spread of the HIVAIDS in the country. Equally important, the H/CBCS is economically efficient to poor countries in the way that resources deemed necessary to institution -based treatment could be put to other important efforts. From psychological point of view, it is largely under the HBCS that HIV/AIDS patients enjoy freedom to express their inner feeling and emotions to the caregivers since the Ethiopian society are largely shay and refrain their inner most feeling to medical personnel in health institutions this intervention mech. In other words, the HBCS allows building trust between patients and caregivers in the

process where, the day-to-day livelihood of patients is shared and to which local councils and trainings are delivered informal social gathering such as coffee ceremony, other cultural and religious events.

It also be noted that currently, there are few NGOs directly engaged in the HBCS activities are located in towns and cities. At this is point of discussion, one can understand that there is more to be done in this regard in the face of the volume of patients the growing rated of prevalence at the national level. Therefore, it is with this set of mind and a strong belief that such useful preventive mechanism must be promoted and scaled up to the rest of the country where fellow patients that have denied access to care and support can get the service within their reach. Good practices, challenges and other innovations form the HBCS process can be shared through proper research uptakes. So is the major driving force that generated the motivation to undertake this particular study under the topic under question through taking the case of Mekdem Ethiopia National Association.

The Government of Ethiopia under the Ministry of Heath has launched the Health Care and Support Program (HCSP) with two consecutive Road Maps in 2010. The first Road Map is aimed at enhancing the activities on expanding antiretroviral therapy (ART) services, and the goal of which is achieving universal access to comprehensive HIV & AIDS services by 2010. Though CHBC is provided in the home, it is part of an integrated approach in the care, support and treatment of HIV/AIDS. CHBC involves a variety of services, provided primarily by an organization (NGO/FBO/CBO) which is linked to various facilities/groups. The whole site approach is complemented by an emphasis on community- and home-based care and on linkages through health posts, kebele-oriented outreach workers (KOOWs), case managers, nongovernmental organization (NGO) outreach workers, mothers' support groups, and other available mechanisms on the ground (USAID,2008).

In line with the global action the Federal Government of Ethiopia has developed important policy and strategic instruments. National Task Force was established in 1985, National AIDS/STD Control Program (NACP) in 1987 (WCC, 2003); two medium term

prevention and mitigation program were implemented between 1987 and 1996 (GFDRE, 2000), produced and implemented guidelines on sentinel surveillance and counseling and also launched a national policy on HIV/AIDS in 1998 (Fekadu&Jemal, 2005). A National AIDS Council was established in 2000. Following this HIV/AIDS Prevention and Control Office (HAPCO) was established. Several relevant policies and regulations further formulated including HIV testing policies for diagnostic and clinical purposes, including professional codes to ensure confidentiality, disclosure policies of HIV testing and resulting provision and comprehensive programs. According to World Health Organization all the aforementioned actions need a collaborative effort of the private and the public sector, NGO/CBOs, the government and individuals and groups.

According CSO Taskforce User's Manual on Charities and Societies (2011) Charities and Societies Agency has registered about 1600 CSOs and out of which more than 1500 are Ethiopian resident and foreign charities working on development and welfare. Therefore Mekidim Ethiopia National Association is among the 1500 NGOs exclusively working in HIV/AIDS intervention that operate on a limited scale, reaching only a small fraction of the population (MENA Brochure 2005). It was established in 1997 by people living with HIV/AIDS and AIDS orphans. MENA is organized to fight against HIV/AIDS, to addresses stigmatization of people living with HIV/AIDS, the lack of care and support, the lack of involvement in prevention programs and other issues affecting people living with HIV/AIDS. People living with HIV/AIDS in Ethiopia often face ostracism, stigma, rejection and isolation by community members, family, and their associates.

Therefore, MENA works to address the human rights of people living with HIV/AIDS and provides ongoing holistic care and support for its members, persons infected with and affected by HIV/AIDS. In its advocacy program, the association is pursuing with the government the provision adequate provision of care and support to people living with HIV/AIDS and orphans. Currently the Association has opened five branches in Dessie, Jimma, Bahir Dar, Nazareth and Shashemene. The number of members, which was 12 in 1997, now reaches more than 15,000 including family members.

1.2 Statement of the Problem

This study mainly intended to assess the home based care and support available to Persons living with HIV/AIDS (PLWHA) and family members of Mekidim Ethiopia National Association (MENA). A holistic and comprehensive care and support program has been developed and best practices introduced for a better adoption and implementation to address the wide ranging needs of HIV infected and affected persons parallel with minimizing the negative national and individual effects of the pandemic and installing the hope of PLWHAs to continue functioning.

No matter what efforts are on the ground, HIV/AIDS is spreading fast; adding new infections to the already existing insufficiently cared for and supported nations. Though funding has increased, because of inefficient utilization and denial of many national leaders about the impact of AIDS on their people and societies, many needy persons do not get access to the basic supports (UNAIDS, 2004). Approximately 90% of people living with HIV or AIDS have extremely limited access to quality care and to new treatment (UNAIDS, 2000).

Therefore, it is critical to determine the most effective means of treating and care for people living with HIV. In sub-Saharan Africa, an estimated 4.3 million people need AIDS care but only about 12% receive it (WHO, 2004). Globally, there are also enormous disparities in spending. per person living with HIV in the United States exceeds 1000 times in Africa (UNAIDS, 2004). In Ethiopia, HIV/AIDS, being an expensive disease that requires a considerable amount of resources from the health system, is estimated costing from 425 to 3140 Birr (average of 1800 Birr) during the course of the illness for hospital care for an AIDS patient (WCC, 2000).

As MENA is working in resource constrained settings, members of the association, people living with HIV/AIDS and AIDS orphans, might not able to get the required care and support services. Evaluating this program helps to pinpoint best practices and to gear interventions towards a best result.

1.3 Objectives of the Study

1.3.1 General Objectives

The main objective of the study intends to assess the practice of the Home -Based Care and Support Program of MENA to its affected clients. The study also has specific objectives:

1.3.2 Specific Objectives

- To identify the types of services(care and support) being delivered to the clients;
- To assess the practice and the nature of the HBCS Programme in relation to the set rules and standards;
- To investigate the achievements and challenges of the HBCS Programmes
- To investigate strengths and constraints of the Association and the HBCS conditions and ;
- To identify the best practices by the HBCS providers in the HBCS process.

1.4 Definitions of Concepts

The Home –Based Care and Support (HBC) is also called Community-Based Care and Support (CBCS) which is defined as

> *The provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death. Home care services can be classified into preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories*. (WHO, 2000).

- **Caregivers** refers to people such as families, caregivers from the formal system e.g. Professionals, caregivers from the non-formal system e.g. NGOs, CBOs. DPOs , caregivers from the informal system e.g. community health worker (CHW), volunteers, other community caregivers and church groups(HAPCO National guideline on home-base care / community-based care,2000).
- **Clients (patients or the program is assist)** refers to individuals who need basic support services to continue to live and/or die in their community and without which they would have been prematurely, inappropriately or unavoidably moved to institutional care. This group of people may include healthy people, at risk or frail older persons, moderate to severe functional disabilities, people recovering from illness, in need of assistance e.g. post deliveries or after specific treatment, terminally ill persons, persons living with HIV/AIDS or any other, debilitating disease and/or conditions e.g. mental illness, substance abusers and any other disadvantaged group/person in need of care and support (HAPCO National guideline on home-base care / community-based care,2000),.
- **Formal System** are health institutions such as hospitals, clinics, health posts etc (Ibid).
- **Non-Formal System** are institutions or organizations that plan, and extend care to clients .These institutions may include NGOs,, CBOs, FBOs and traditional healers and leaders (Ibid).
- **Formal caregivers** may include medical professional such as physicians, nurses, health officers etc that provide care and support to clients (WHO, 2000)
- **Informal caregivers** are people community health worker (CHW), volunteers, other community caregivers and church groups (WHO, 2000).
- HBCS is not intended to mean "second class care" or "cheap care" for those who cannot afford hospital care. For commonly occurring diseases/conditions can be effectively managed at home (WHO, 2000).
- **Institution -B**ased are and Support (IBCS)** treatments being given to clients under formal institutions such as hospitals, clinics, etc (HAPCO National guideline on home-base care / community-based care, 2000).

- **Palliative care** is a philosophy of care which combines a range of therapies with the aim of achieving the best quality of life for patients (and their families) who are suffering from life-threatening and ultimately incurable illness. Central to this philosophy is the belief that everyone has a right to be treated and to die, with dignity, and that the relief of pain - physical, emotional, spiritual, social - is a human right and essential to this process (UNAIDS, 2003).
- **Operational Definition of Home –Based Care and Support** the study has tried to define the HBCS in such a way that it fits in to both the international practices and Ethiopian realities on the ground in general and the approaches and methodologies of Mekdim Ethiopia in particular. Therefore, For the purpose of this particular study, the HBCS is defined as a set of medical, psychological and economic care and support given to helpless HIV/AIDS patients by the community within a community.

1.5. Limitations of the Study

Despite all the efforts made to accomplish this study, some practical limitations were the sensitive nature of both HIV, its use of small number of study participants and incomparability of this study with others due to the absence of previously conducted evaluation reports on the home based care and support program of MENA.

Strength

There was no review and evaluation report on the home based care and support program of MENA either by MENA or others. Therefore, this study will provide insight on the existing home based care and support services and indicate areas of interventions. Further, it helps to be a base for similar and extensive studies

1.6. Organization of the Thesis

The study is organized in five chapters. The first chapter deals with the introduction of the study. The Second chapter is dedicated to the review of the related literature. The third chapter describes the study design and methodologies used. The presentation and

analysis of the data collected and interpretation of the findings are included in chapter four. The fifth chapter presents summary, conclusion and suggestion for action**.**

The methodology is designed to include measurable facts, developments from client's caregivers, and experts of MENA. Experts and officers implementing the program in MENA and beneficiaries/ clients/ of the association were an integral part of this study. In the assessment of the home based care and support program of MENA, the guide and indicators developed by World Health Organization of the year 2000 is used.

CHAPTER TWO: REVIEW OF LITERATURE

2.1 Introduction

HIV/AIDS has brought multifaceted problems to all endeavors of the development of human beings. The intensity of these problems inquired a holistic and comprehensive intervention. One of these vital interventions is the provision of care and support services for persons infected with and affected by HIV/AIDS. According to WHO (2004) these care and support services need to be broad and comprehensive which include clinical care, psychological support, socioeconomic support, involvement of people living with HIV/AIDS and their families and respect for human rights and legal needs. Any intervention to be effective and efficient obtaining the determined commitment of all persons should be founded on concrete and strong rationale and principles.

2.2 HIV and AIDS at Different Level

As various UNAIDS sources indicate AIDS epidemic spread at alarming rate and it seems that nothing stops its devastating feature of the disease. It affects everybody without any distinction based on conventional boundaries, geographic location, race, nationality, color, sex, age, religion etc and time bound (Judy, 2003). Globally, it is the fourth most common cause of death especially to the productive age force. There is also variation in the pattern of spread among countries, within countries like urban and rural areas (UNAIDS, 2000).

According to 2005 UNAIDS report, the number of people living with HIV and AIDS continues to grow from 37 million in 2003 to 40.3 million in 2005. In addition, the estimated total people newly infected with HIV are close to 5 million, where as total AIDS deaths are 3.1 million. HIV/AIDS has killed more than 25 million people since the emergence of the disease. Now days, HIV and AIDS infection reaches at the highest level with multi dimensional challenges (UNAIDS, 2005).

AIDS pandemic make differences among developing and developed nations. In industrialized World, anti retroviral drugs and other supportive medicines are available,

which reduce the speed of HIV infection to develop AIDS. As a result of medicines and technology, the number of deaths due to AIDS decreases in the developed countries. Regarding this, in America AIDS related deaths approximately 70 percent from 1995 to 2000, from 51,670 deaths in 1995 to 15,603 deaths in 2001(Shalina Mehta and Suninder K.Sodhi, 2004).

On the contrary, in developing countries where AIDS is the most common disease results in many forms such as cut overall life expectancy, infant mortality, HIV positive pregnancies and births. As different sources indicate mother to child transmission of HIV is prevented in the industrialized countries and reduces below 3 percent. Few middle-income countries in Asia and South America have also prevention work on mother to child obtained undeniable results (Shalina Mehta and Suninder K.Sodhi, 2004).

Apart from health problem HIV has different impact on women and children. Majority of women all over the World are at risk of contracting HIV because of their biological anatomy and exposed to social stigma and pressures. Some culture imposed negative influence against women and does not give their right (CPA2005). In addition, children are orphaned by AIDS and remained without guardians. These children lost the ownership of their fathers' property by close relatives and even relatives forced the children to leave their home (CPA2005).

AIDS pandemic has also critical impact on economic and social development. It mainly affects the most vital and productive segment of population such as adults between 20 and 49 years old (MoH, 2004).

2.3 HIV and AIDS in Sub Saharan Africa

Sub-Saharan Africa region is one of the hot zones and severely affected by HIV and AIDS epidemic throughout the World (UNAIDS, 1999). HIV and AIDS is the leading cause of death of young women and men in the early life of age (Shalina Mehta and Suninder K.Sodhi, 2004).

It also causes productive loss, increase number of AIDS orphan, family disintegration, loss of skilled professionals, shortage of civil servants, food insecurity; decrease individual and households income (UNAIDS, 2004). The region accounts over 10 percent of the World's population but out of this figure above 60 percent of (25.8 million) all people living with HIV and AIDS. Still high prevalence rate of HIV and AIDS incidence seen in the region.

For instance, the UNAIDS 2005 report estimates 3.2 million people become newly infected and 2.4 million adults and children died of AIDS (UNAIDS, 2005). In the region, religious organizations have confusion in dealing with HIV and AIDS and have taken time to accept HIV/AIDS epidemic as a disease rather than God punishment (CPA, 2005). Later on, religious leaders have changed the previous thought and take full responsibility in teaching, support and care of PLHA. Churches also incorporate HIV and AIDS in the curriculum of its theological medium level schools. It also offers AIDS awareness education for the church members, local communities and youth. Organize short-term courses for church workers, seminars and panel discussion. The graduate of the Bible schools teach on HIV and AIDS in their daily pastoral work and ministry. All these efforts brought the decline of HIV/AIDS prevalence rate in countries like Uganda (CPA2005). The other reason for the decline of HIV/AIDS is strong community organizations involvement in provision of different services such as care and support, mobile home care to PLHA.

Motivate the community and make campaign for educating the people about AIDS to avoid this infection. Mobilize communities to support changes in social norms and harmful practices that encourage risk reduction. Give training to many community workers to provide basic care and health education about AIDS. All these effort consistently high levels of donors support the programs and activities (UNAIDS 1999).

2.4 HIV and AIDS in Ethiopia

HIV infection was first discovered in Ethiopia in 1984 and the first AIDS case was reported in 1986. HIV and AIDS prevalence was low in the early 1980s and increased rapidly through the 1990s and rose from an estimated 3.2% of the adult population in 1993 to 7.3% (MoH, 2000) by the end of 1999(NAC, 2001).

The 2003 report shows that, HIV prevalence is higher among women (5%) than men (3.8%) and higher in the urban (12.6%) than the rural areas (2.6%). In 2003, there were also 197,000 new infections, 98,000 new AIDS cases and 90,000 AIDS deaths in adult population in (MoH, 2004*)*. A total number of 128,000 HIV positive pregnancies and estimated 35,000 positive births occurred (MoH, 2004)**.** Among children between ages 0-14 years, there were 35,000 new HIV infections, 25,000 new AIDS cases and 25,000 deaths (MoH, 2004). 4.6 million Children under the age of 17 in the country are estimated to be orphans for different reasons of which 537,000 were due to AIDS. The highest prevalence rate is recorded among the group of 15-24 years of age representing recent infections. 91% of infections occur among adults between 15-49 years. The people living with HIV/AIDS in 2003 are 1.5 million (1.4 million adults and 96,000 children) (MoH, 2004). HIV and AIDS prevention and control office of Addis Ababa (HAPCO) technical document summarize the epidemic AIDS in 2005 shows as follow: Number of people living with HIV are 251,379 and people newly infected 30,323 and AIDS deaths 23,612. The Addis Ababa administration HIV prevalence rate is 14.5 percent and for women 15.9percent and men 13.0 percent.

In Ethiopia, 91percent of reported AIDS cases are in the age group between 15-49 years. In this age group, close to 87% of infections are due to heterosexual transmission. The peak ages for new HIV infections are 15-24 for females and 15-34 for males while the peak ages for AIDS cases are 20-29 for females and 25-34 for males (NAC, 2001).

2.5 Impact of HIV/AIDS in Ethiopia

The impact of HIV and AIDS in Ethiopia has devastating nature and exacerbates different socio-economic problems (NAC, 2001). Different data sources show many people infected and affected by HIV/AIDS in the country and most challenges are manifested in the urban areas, lead to shortage of various services and increase the cost of medical care. (NAC, 2001). HIV/AIDS is known as a disease and leading causes of adult morbidity and mortality in the country. As a consequence, it has various influences on population growth and decline of life expectancy as compared with the previous decades (Lisa, 2003). AIDS has increased the number of deaths and there will be a cumulative total of 5.3 million AIDS deaths by 2014 (Ibid).

As different sources indicate, the majority of AIDS cases are between the ages of 20 and 49 years old. These ages are the most important and crucial time for active economic production and to establish family and become parenting (MoH, 2004). AIDS affects the household incomes and consumption patterns and reducing income, savings and remittances and increasing expenditures on health care and funerals ceremony and exposed the family to economic vulnerability and psychosocial problems (Lisa, 2003). AIDS made a number of children become orphan in the country. As a result, orphan children are vulnerable to malnutrition, illness, abuse, child labor and sexual exploitation. In addition, they suffer HIV/AIDS related stigma and discrimination (Lisa, 2003).

Traditional extended families ability to foster orphans care reduced due to AIDS burden. Even, small girls will be more responsible than boys after the death of both parents, may become heads of households responsible for caring the younger siblings (Lisa, 2003).

HIV/AIDS has a serious impact on agriculture sector especially food and cash crop production and loss of labor force. Because of this, AIDS makes it difficult for families to feed themselves and less probable to be food crop self-sufficient. Thus, AIDS could affect both the production of cash and food crops (Lori Bollinger, John Stover and Elini Seyium, 1999).

AIDS also has an effect on the industrial sector. Since prevalence of HIV infection is higher in urban areas, the industrial workforce is hardest hit than the rural workforce (Lori Bollinger, John Stover and Elini Seyium, 1999). HIV/AIDS also reduces productivity through increased absenteeism due to illness, death, and decrease in the number of trained manpower. It also increased costs in provision of medical services and treatment (Lori Bollinger, John Stover and Elini Seyium, 1999***)***.

2.6 Rationale for Care Support Service Provisions

In the Ethiopian context caregivers from the formal system e.g. Professionals, caregivers from the non-formal system e.g. NGOs, CBOs. DPOs , caregivers from the informal system e.g. Community Health Worker (CHW), volunteers, other community caregivers and church groups(HAPCO 2000). The reason behind for the HBCS largely in poor countries is that, given the fact that there are fewer health institutions , poor access and communication and limited resources verses the volume of patients . As the number of PLHA increases, the gap continues to widen between the demand for, and the availability of health care services. Relying mainly on the family and community as caregivers, community home-based care (CHBC), has become a significant contributor in the treatment, care and support of those affected by HIV/AIDS.

According to the World Health Organization (2000), the rationale for care and support mainly relays on the fact that care and support is a human right and nations who ratified the Human Right Conventions are required to provide the care and support accordingly. Besides, the continued spread of the HIV/AIDS pandemic and its devastating social and economic effects has increased the urgency of expanding interventions in a comprehensive ways (FHI, 2004). The rational as per the intention of WHO (2000) and Family Health International (2003) is summarized as follows:

• Contributes to the prevention of HIV infection - Care provision offers an opportunity to discuss with the client and significant others how they might prevent further spread of the infection, and support them in their choices to do so (WHO, 2000).

- Care and support for PLWHA decreases the spread of infectious diseases. HIV/AIDS care and support services helps destigmatize HIV, improves demand for HIV voluntary counseling and testing services, and allows for early management and prevention of infectious diseases (STIs) (FHI, 2001, WHO, 2000).

- Care and support improves the Social and economic status. Care and support for PLWHA improves health of PLWHA which later help them to involve in economic activities (WHO, 2000).

- Care and support for PLWHA builds confidence and installs hope. As the quality of life of PLWHA improves, hope will be instilled to the benefit of the individual and the family, and as a result to the society (WHO, 2000).

- Care and support for PLWHA supports the Greater Involvement of People living with HIV/AIDS (GIPA) in the fight against the epidemic. Publicly acknowledged involvement helps reduce stigma and discrimination, and sends a signal to society to realize that HIV is also their problem, and motivates them to do something about it (WHO, 2000).

- Helps restore dignity to PLWHA. Providing hope and restoring dignity help to decrease stigma (FHI, 2003).

2.7 Principle and Values of Care and Support Service

The provisions of any services needs to systematically and well designed and based upon widely accepted principles and values. The World Health Organization principles are devised to achieve the greatest devotion and commitment required for resources allocation of care and support provision based on basic principles and values of respect, equity, quality of services, efficiency and effectiveness, accessibility and availability, and sustainability as to make services available and accessible to as many people as possible (WHO, 2000). These principles and values are well articulated in the objectives of the program.

2.8 Objectives of HIV/AIDS Care and Support Program

To address the wide-ranging of needs of PLWHA, based on the principles and values discussed above, HIV/AIDS care and support programs as per WHO standards (2000, 2004; FHI, 2003) are required to have the following goals and objectives. Major objectives are:

- Reducing morbidity and mortality from HIV/AIDS and related complications
- To improve the quality of life of both adults and children living with HIV/AIDS and their families,
- To improve the survival of PLWHA

2.8.1. Specific objectives:

- To strengthen and promote opportunities for prevention of HIV transmission
- To expand greater involvement of PLWHA
- To reduce the impact of HIV on the TB and HIV-related diseases
- To mitigate the socio-economic and psychological impact of HIV on individuals, families, communities, countries and society at large
- To improve HIV care for vulnerable populations such as young people, pregnant mothers, drug users and orphans, whose access to care is limited
- Ensuring equitable access to diagnosis, health care, pharmaceuticals and comprehensive supportive services, and
- Promote prevention opportunities within care, treatment and support clinical encounters

2.9 Comprehensive HIV/ AIDS Care and Support Program

The needs of PLHA are wide ranging. As HIV infection and illness steps forward, the types of services required also changes (Family Health International, 2003a). Therefore, a complete and a broad range services that include supportive and complementary services are required to address these wide ranging needs of PLHA and their families with the implementation of broad ranging program and comprehensive approaches(FHI, 2003, 2004).These broad and comprehensive care and support services need clinical. Care, psychological support, socioeconomic support, involvement of people living with HIV/AIDS and their families and respect for human rights and legal needs (WHO, 2004). According to Family Health International (2001, 2003) and WHO (2004) the care and support needs of people living with HIV/AIDS and their families have been identified in four interrelated domains and this is presented by the figure below.

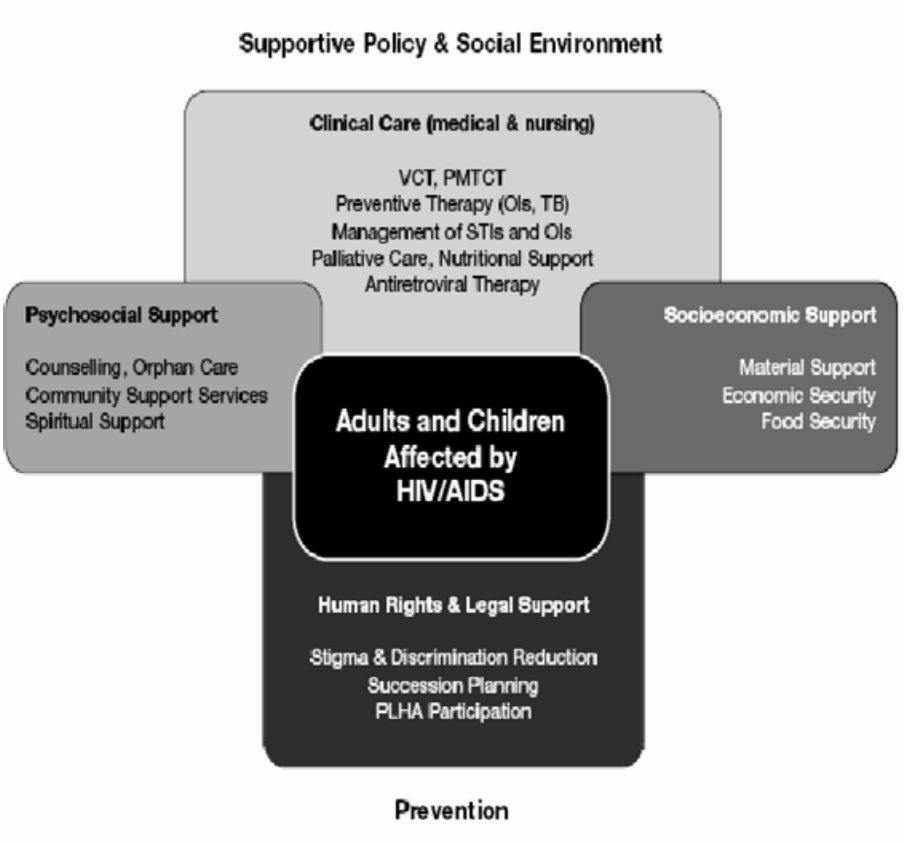


Figure 2.1 The Four Main Domains of HIV/AIDS Care and Support Services
(Source: Family Health International, Treatment Division, WHO, 2004, p.6.)

The same sources further illustrated and discussed these four interrelated care and support services as follows:

- *Clinical needs/Medical and nursing care* People living with HIV/AIDS need medical and nursing care that will reduce HIV morbidity and mortality and optimize their quality of life. Such services are: treatment information and treatment, appropriate diagnosis, counseling and testing for screening and diagnostic purposes (including voluntary counseling and testing), prophylaxis of opportunistic infections, management of HIV-related illnesses, including opportunistic infections (OIs),control of tuberculosis and management of sexually transmitted disease, management of HIV disease with antiretroviral combination therapy, palliative care(*therapies with the aim of achieving the best quality of life for patients*), access to drugs related to HIV/AIDS provision of Highly Active Antiretroviral Therapy (HAART) and clinical monitoring; interventions to reduce the mother-to-child transmission of HIV, support systems such as functional laboratories and drug management systems, nutritional support, health education measures, adequate universal precautions in clinical settings; and post exposure prophylaxis (WHO, 2004).
- *Psychosocial support and counseling* improve quality of life through helping individuals, couples, and families affected by HIV cope with their fears and emotions (FHI, 2003a). Psychological support includes counseling (initial and follow-up) services to meet the emotional and spiritual needs of people living with HIV/AIDS and their families, support to enable disclosure and risk reduction strategies, medication adherence, and end of life and bereavement support (WHO, 2000; 2004).
- *Socio Economic needs* people living with HIV and their families are confronted with additional challenges throughout the course of the disease, including isolation, loss of income, medical and transport expenses, funeral costs, and the unmet material and social support needs of orphaned children for shelter, nutrition, clothing, education and other daily living needs and necessities; and poor or lack of involvement of HIV-positive individuals and their families in

service planning and delivery to ensure care, treatment and support programs intended for them address their felt and prioritized needs and include human rights. Most of these problems are directly or indirectly engendered through the economic impact of HIV/AIDS on the individual, the family and the community (FHI, 2001, 2003, WHO, 2004). To mitigate these negative consequences of HIV/AIDS, efforts must be made to meet the material and social support needs within communities ensuring nutritional and ensuring nutritional (WHO, 2004); build or sustain economic resources for individuals and their households to support the creation of community safety nets and networks including micro credit schemes; housing; food support; helping hands in the household; health insurance schemes that include HIV/AIDS care and treatment; and planning and support for orphans and vulnerable children in households and communities (WHO, 2004). Such efforts yield better and longer-lasting results when they are undertaken with an emphasis on supporting the natural social networks of immediate and extended families (FHI, 2001).

- *Respect for human rights and legal needs* People infected with and affected by HIV face stigma, discrimination and other violations of their human rights in their home, neighborhood, and society. Therefore, services that properly and meaningfully address stigma, discrimination and any other right violations in to care and support including succession planning and protection of property are required in the comprehensive HIV/AIDS care, prevention and support programs. Legal assistance is often needed, for example, to ensure that laws protecting the rights of those infected and affected by HIV are applied, to help people living with HIV write wills, and to safeguard the property and inheritance rights of surviving family members.

Besides, the aforementioned dominant care and support service components care for the caregivers is supplemented to provide comprehensive services.

2.10 Care for the Caregivers

Caring for anyone with a serious chronic illness is a physical and emotional challenge for even the most dedicated caregivers (FHI, 2003a). This is particularly true for nurses, counselors, volunteers, and caregivers in the home who provide the bulk of care for PLHA.

These caregivers also need support to help them do their jobs well, avoid burnout and keep themselves going and free of infection and remain free of infection (WHO, 2000). According to the different experiences of FHI (2001), some of the ways to address the needs of caregivers are activities that include creating a work environment where work is appreciated, shared and well supervised, arranging regular social events, better recognition, incentives, peer support, access to post-exposure prophylaxis at the institutional level, and additional ongoing training opportunities; VCT services for health staff, antiretroviral treatment and institutional policies for HIV infected staff (WHO, 2000).

2.11 Continuum of Care and Support

Each person living with HIV/AIDS has different needs, depending on the stage of illness and the circumstances. Provision of comprehensive care and support across a continuum from home and community to institutional services and back will ensure the specific medical, psychological, socioeconomic and legal needs of people living with and affected clients and their families (FHI, 2001, 2003). In this comprehensive approach, each service is linked to and reinforces other services and interventions (WHO, 2004).

The range of care and support can be offered by several providers. Their partnership and collaboration is essential to provide HIV infected and affected persons with a continuum of care and support (FHI, 2004). A continuum is built around a network of resources and services to provide an affordable, timely access to appropriate services and comprehensive range of services in various settings, including the home, community projects, clinics, and hospital (FHI, 2001, 2003). Strong referral linkages among the various service partners ensure a continuum of care, avoid duplication of services and

maximize available care and support resources (FHI, 2001a). The figure below illustrate the referrals and the elements of comprehensive care and support for affected families and the provision of care among the various partners across a continuum from home and community to institutions and back (FHI,2001).

The above figure clearly shows the need of active referral and linking and complementing services of the various providers for effective and efficient service provisions. The same figure entails that everybody has contribution and is linked from one end to the other end. The whole process calls strong involvement of HIV/AIDS infected and affected persons in the planning and delivery of comprehensive care to ensure that HIV/AIDS care; treatment and support programs intended for them address their needs, reinforce adherence, prevention and care, promote health-seeking behavior and respect their human rights (WHO, 2004).

2.12 Levels of HIV/AIDS Care and Support Services

HIV care and support programs need to be developed, implemented and strengthened in line with the increasing needs of HIV infected and affected persons. This is because as HIV infection steps forward, the types of services needed also change (FHI, 2001).Therefore, interventions need to be tailored to the local context, the stage of the epidemic and the existing community and national resources based on properly facilitated strategic planning to identify and prioritize the essential elements of the program based on the stage of the epidemic, contextual factors, cost, cost-effectiveness, feasibility and sustainability in a specific setting (FHI, 2001b). In each setting, however, difficult choices have to be made about the level of care and support that is feasible and affordable in the short term and what can be attained in the future. WHO has developed a model of prioritization of care and support options in relation to resource availability. The advantage of this model is that it covers not only the health sector but also the community and home based care activities through a step-by-step approach (WHO, 2000).

There exist several cost-effective HIV/AIDS care interventions. Key activities for HIV/AIDS care and support are presented in the table below grouped according to their complexity and cost.

Table 2.1Care and Support Activities According to Need, Complexity and Cost

Care and Support Activates, according to need, complexity and cost
• HIV voluntary counseling and testing
• Psychosocial support for PLWHA and their families
• Palliative care and treatment for common OIs: pneumonia, oral thrush, vaginal candidias is and pulmonary TB
• Nutritional care
• STI care and family planning services
• Cotrimoxazole prophylaxis among HIV –infected people
• Recognition and facilitation of community activities that mitigate the impact of HIV infection (including legal structures against stigma and discrimination)
ALL THE ABOVE PLUS
• Active case finding (and treatment) for TB, including for smear negative and disseminated TB, among HIV-infected people
• Preventive therapy for TB among HIV- infected people
• Systemic anti fungal for systemic mycosis (Such as Cryptococcus)
• Treatment of HIV-associated malignancies: Kaposi's sarcoma, lymphoma and cervical cancer
• Treatment of extensive herpes
• Prevention of mother to child transmission of HIV
• Post exposure prophylaxis of occupational exposure to HIV and for rape
• Funding of community efforts that reduce the impact of HIV infection
ALL THE ABOVE PLUS
• Triple antiretroviral therapy
• Diagnosis and treatment of opportunistic infections that are difficult to diagnose and /or expensive to treat, such as a typical mycobacterium infections, cytomegalovirus infection, multi resistant TB, toxoplasmosis, etc
• Advanced treatment of HIV related malignancies
• Specific public services that reduce the economic and social impacts of HIV infection

Source: WHO (2000:9) Key elements in HIV/AIDS care and support activities.

As the above table shows, there are three levels of HIV/AIDS care and support interventions on the basis of their complexity and cost. According to resources availability, the focus might be on the provision of essential (basic) care interventions on the provision of intermediate cost/complexity care interventions or on the provision of more advanced and highly complex care interventions care and support co-exist.

Whenever more resources (human, technical and financial) are available, HIV/AIDS care and support can be scaled up to increase coverage and/or additional elements of care can be considered.

2.13 Monitoring and Evaluation

Resources invested in the care and support services in any of complexity and cost should be result-oriented and there should be corresponding concrete quantifiable results. Evaluation helps to compare planned performance with the actual outcome (Brody, 2005). Programs will be effective only if they are consistently evaluated to measure effectiveness, efficiency, quality, usage and acceptability in the community (WHO, 2004). There are essential elements of monitoring and evaluation developed by World Health Organization regardless of the program type: Formative Evaluation (Determines Concept and Effectiveness Evaluation (Assesses Outcome and Impact), Cost-Effectiveness Analysis (assess Sustainability Issues) (FHI, 2001).

This evaluation study of the care and support program of MENA is of process evaluation type. Indicators and measurement tools appropriate to compare the quality, extent and coverage of care and support services are developed with standards and norms (WHO, 2004). An evaluation approach that uses multiple data collection methods, both quantitative and qualitative, is suggested to address diverse evaluation needs than a more limited approach (FHI, 2001). The literature presented in the above section briefly shows the important areas that any care and support programs on HIV are supposed to consider. Therefore, this review and evaluation of the care and support program of MENA relay on the literatures presented here. The type of evaluation employed here is that of process evaluation. The researcher was able to see one study made in November 2004 by HAPCO on HIV/AIDS care and support intervention response in Addis Ababa which shows the state of care and support. No special evaluation report made on care and support interventions obtained. This study will give some insights for future review and evaluation attempts. Design), Process Evaluation (Monitors Inputs and Outputs; Assesses Service Quality).

CHAPTER THREE: STUDY DESIGN AND METHODOLOGY

3.1. Introduction

In reviewing and evaluating the home based care and support programs of MENA the study basically used quantitative methods observation, and retrospective review of relevant documents, individual in-depth interview and key informant interview. The methodology is designed to include thoughts and opinions of beneficiaries and experts of MENA .Experts and officers implementing the program in MENA and beneficiaries/ clients/ of the association were an integral part of this study. In the review and evaluation of the home based care and support program of MENA, the guide and indicators developed by World Health Organization of the year 2000 is used.

3.2. Description of the Study Area

HIV/AIDS is a deadly disease well prevailed in economically developing nations of the world. The rate of HIV/AIDS prevalence is high in urban centre. As Addis Ababa is the political and economic centre of the country, the rate of HIV/AIDS prevalence is expected to be high. Recent reports and assessments showed, there have been marked increases in the number of health facilities and sites providing HCT, PMTCT, and ART services results in a tendency of decline of newly infected people.

Number of Health Facilities Providing HCT, ART and PMTCT and Distribution of HIV/AIDS Counseling Service of Addis Ababa City by Subsequent Years 2000-2004 E.C.

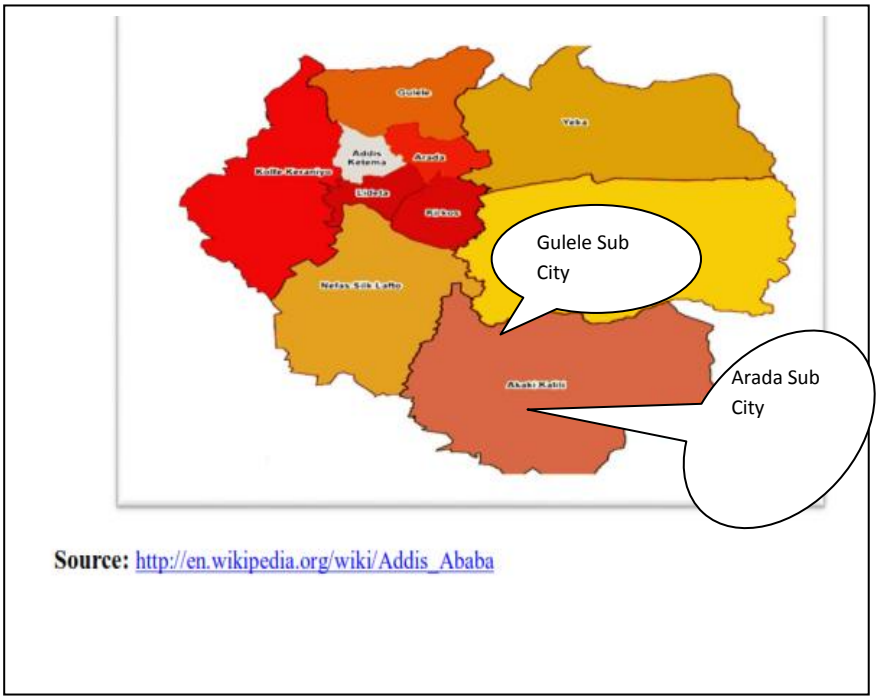
Table 3.1 Indicators of Health in Addis Ababa

Detailed information on HIV/AIDS services	2000 E.C	2001 E.C	2002 E.C	2003 E.C	2004 E.C
Number of Health Facilities Providing HCT	166	175	224	225	230
Number of Health Facilities Providing PMTCT Services	35	54	59	72	104
Number of Health Facilities Providing ART Services	*	53	*66%	*	*
Number of People who get HCT service	260,754	203,955	443,791	207,545	*
People who are HIV positive from All Who Get HCT Service	26175	17715	15578	14812	*
People Living with HIV/AIDS (PLWHA)	*	190558	*	*	*
New HIV Infection All Age People	*	22214	*	*	*
New HIV Infection Children	*	906	*	*	*
ANC Clients in Facilities Providing PMTCT	*	49372	*	54667	72504
Pregnant Women Tested for HIV	*	36659	*	62558	66750
Pregnant Women Tested Positive for HIV	*	1509	1976	3643	1864
Number of people getting ART services	31457	40084	47887	54667	44151
Institutions providing ART service	47	49	52	54	53
Number of Mothers who get Prenatal service	*	49,372	54,698	75,237	72,504
Number of Mothers getting ART services	*	1,337	1206	1689	1595
HIV/Prevalence Rate		8.5%	*	*	5.7%

Source: FMoH and Addis Ababa City Bureau of Health 2004 E.C Annual Report

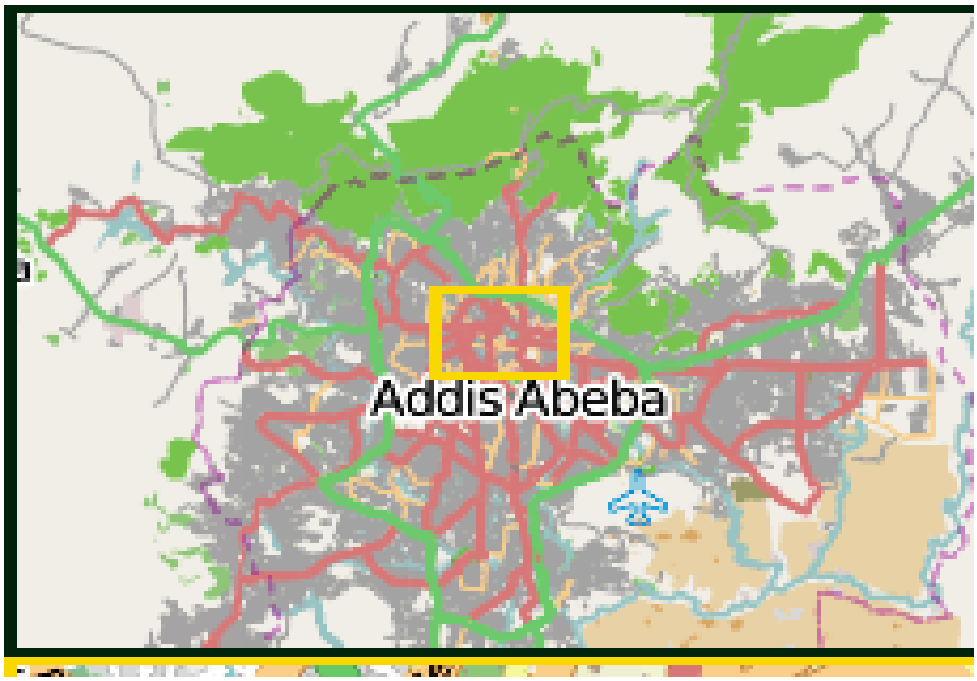
Note: *Data are not available 8.5% * * 5.7%

From the above illustrates total services of HIV/AIDS in the city in the subsequent years from 2000-2004 E.C. The number of health facilities providing HCT was increasing from 166 in the year 2000 to 230 in the year 2004 E.C. As a result of increment in HCT facilities the people who get the service made progress from 203,955 to 443,791 in the year 2002 in the year 2001 E.C. But lower in 2003 E.C. The number of people who got ART service also considerably increased from year to year. In 2000 E. C it was 31,457 and gradually increased and reached 44,151 in the year 2004 E.C. With the expansion of health facilities providing HCT, the rate of HIV/AIDS prevalence declined from 8.5% in 2001 to 5.7% in 2004 E.C.



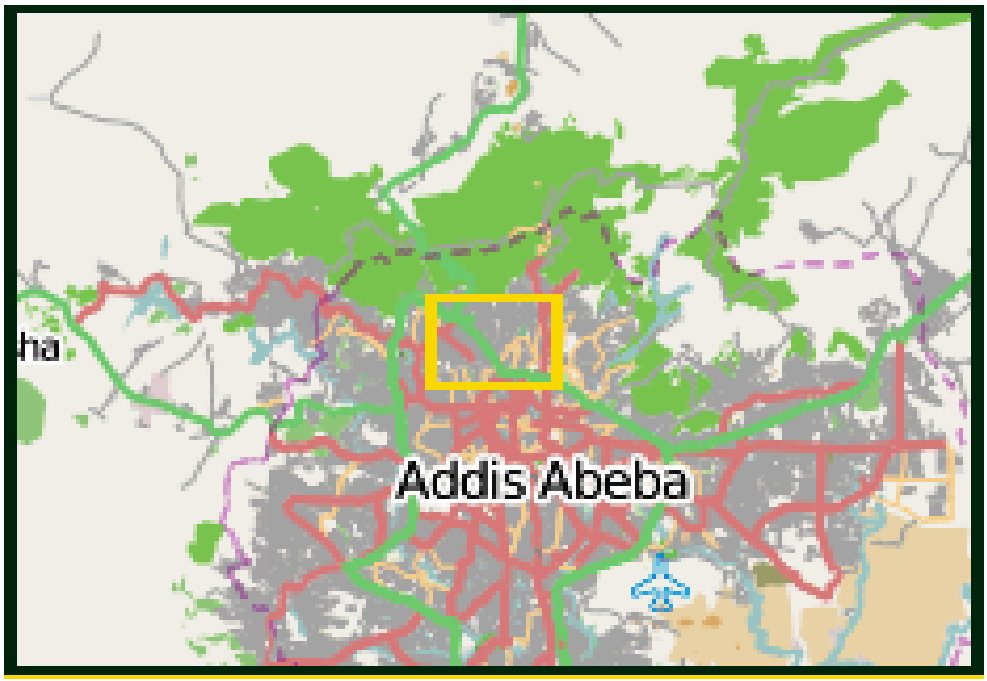
Source: http://en.wikipedia.org/wiki/AddisAbaba

Figure 3.1 Map 1 Administrative Map of Addis Ababa



Source: (Google Map 2015)

Figure 3.2 Map 2 Gulele Sub City



Source: (Google Map 2015)

Figure 3.3 Map 3 Arada Sub City

3.3. Study Design and Methods

This assessment is purely a process evaluation The purpose of this particular study, therefore has attempted to make an overview on MENA's the activities involving the provision of care and support to patients in two project sites located in Arada and Gulele Sub-Cities in the city of Addis Ababa , Ethiopia. The study is based on the quantitative approach of research undertaking so that primary data were collected from the agreed sample population of the each project sites. Information gathered were analyzed and interpreted to make the study analytical and rational for the readership. There three set of respondents that contributed their accounts for the success of the study. That are 75 patients that are directly getting the HBCS from MENA, 7 Caregivers that are directly engaged in providing patients of clients with medical, psychological and socio-economic support and a project coordinator who directly supervises the day-to-day activities of

MENA's HBCS process. In addition, reports, fact sheets and project documents were consulted.

3.4. Universe of the Study

Mekdem Ethiopia National Association has branches in Dessie, Jimma, Bahir Dar, Nazareth and Shashemene towns. The study covers home based care and support program of Addis Ababa branch of Arada and Gulele Sub cities.

3.5 Sampling Methods

The study will employ a Simple Random Sampling that allows to make a quantitative analysis from limited study population. Therefore from a total of beneficiaries 1000 households, 75 parents (50% are mothers) will be considered. Secondly, the study will use Purposive Sampling technique include professionals and experts involved in the program. Accordingly, a Project Officer of the HBCS from Mekdem will be included in addition to the 7 caregivers from each cites.

3.6 Data Collection Instruments and Procedures

In order to collect quantitative and qualitative data, questionnaires were developed for beneficiaries, care givers and officials of the association.

In addition, a checklist was prepared to extract data from project document, reports, fact sheet and other written documents. All the elements of review and evaluation tools designed and developed based on the WHO and the national HIV/AIDS care and support monitoring and evaluation guidelines.

In order to assure discussion and interview guides for their language simplicity, understandability and clarity the researcher pre-tested them in an organization called Integrated Service for AIDS Prevention and Support Organization (ISAPSO). Accordingly, some relevant and minor changes were made and the final versions of the data collection tools were developed.

As part of the understanding of the objective of the assessment of the program special attention was taken to collect data on process evaluation principles that are applicable to the local context and the scope of the stated objectives. I have observed that almost all beneficiaries who took part in the interview session looked in great shape and made me convinced that the counseling they are receiving about healthy leaving is working pretty well.

The researcher has made closely interviewed beneficiaries, care givers and officials from MENA. Oral consent from beneficiaries, care givers and written consent from MENA officials obtained ahead of interview and discussion dates. All the interviews went smoothly with no problems. .

3.7. Data Processing and Analysis

MENA is working in a resource constrained environment. To help MENA in providing quality services with the existing scarce resources, to reinforce its activities to a higher standard and to manage programs from global perspectives, literatures pertinent to the developing countries recommended by United Nations working in HIV/AIDS and health were reviewed and analyzed.

Retrospective review of documents - Books, electronic data sources, project proposals, reports, national HIV policy, strategic document and guidelines were reviewed to get information on globally recommended services for developing countries, existing program activities in the association, the prevailing national program and the government concern and involvement and best practices, standards and guides in monitoring and evaluating care and support programs.

Observation –Home visits, Service/support provision and observation on interactions made to collect data. Three days observation was made to scrutinize physically existing services/supports and participation of the beneficiaries in service delivery. In all the data collection times and methods participant and non participant observation made to look interaction of the beneficiaries among themselves and with the organization, treatment and handling of the beneficiaries with respect to human rights and legal needs.

The evaluation information to be of help to any organizations working on HIV/AIDS home based care and support interventions and to address the stated objectives of this review and evaluation, data were gathered and analyzed by adapting the indicators developed by WHO to the local condition and against each of the objectives of this research. In both the review and evaluation sections data was synthesized and analyzed using no special data processing software. Information obtained from observation and interview analyzed quantitatively and qualitatively and triangulated to integrate them. Efforts were made to organize and analyze data on the basis of empowerment evaluation (Youn & Terao, 2003) and showing the concrete improvements achieved on the quality of the life of PLWHA and orphans due to the home based care and support program of the association.

3.8 Ethical Consideration

To collect reliable information the review and evaluation of the home based care and support program of MENA, from social work point of view, the following principles employed:

- systematic information-gathering techniques devised to develop understandings by examining a situation fully and not from a single, personal point view
- making assumptions is avoided without carefully checking them out
- possible sources of bias and error identified and avoided

Ethical issues were a concern and even more of an issue in collecting data for this study. Confidentiality was assured for all survey participants and maintained throughout the process and hence information was collected in confidence with the purpose of informing all about the review and evaluation. Significant time was taken to ensure that survey participants understand their rights and voluntary participation with an effort of convincing them the benefit of the findings in improving interventions.

CHPTER FOUR: DATA ANALYSIS AND INTERPRETATION

4.1 Introduction

As has been mentioned the study is entirely based on quantitative analysis method. Therefore, interview schedule has been prepared and distributed to respondents (patients, caregivers and MENA's Project Officer. The review of documents revealed that MENA has clearly set goals and objectives. In line with attaining these goals and objectives, a MENA official was interviewed to determine to what extent services are implemented meeting the goals and objectives of the association. The official stated that MENA is implementing pertinent activities and services to attain the goal and objectives but with budget constraints there is some limitation to achieve them properly.

4.2 Socio –demographic Characteristics

The socio economic and demographic landscape of the sample population has been carefully documented and presented as follows. Accordingly, 30 percent are engaged in micro business, 25 are daily laborers and the rest are engaged in other forms business such artisanship and brokering. And each has an average monthly income of close to 1000 ETB. Their education level ranges from illiteracy to high schools completion therefore, 50 percent of the sample population have completed secondary school studies (9th-12th grade),followed by primary school(1-8thgrade) and 5 percent of which have graduated in diploma and first degree.

The religion profile of respondents is largely dominated by Orthodox Christains-45 percent, followed by Muslims and Protestants having each 25 percent and 5 percent are Catholics. Their ethnic composition is also relatively similar. Oromos are the majority (30 percent) followed by 25 percent Amharas and the remaining coming from a compositions of other ethnic groups in the country (Survey Result 2015).

The housing and habitation conditions of patients are composed of houses made of mud and iron sheet and bricks while some are lodgers and others are private owners. So 50 percent of the target populations are living in mud houses while 45 percent are in bricks

and the rest live in shelters made of plastics, woods and other local material. More than half (55 percent) of the target population are loggers, while 25 percent and 20 percent said that patients are living in their private shared respectively. As to patients contracted the HIV/AIDS virus, that led to the care support program of the HBCS, 25 percent of the respondent share their recollection that it was through un safe medical examination and treatment for other diseases, while 20 of them through unprotected sex and the rest confirmed that they have no recollection of who but after medical examination, they were supposed to get remedies for prolonged sickness. And all of whom have been living with the virus more than a year (Survey Result 2015).

As it stands now 95 percent of the sample population is getting immediate case and support form MENA in time of urgency. However, the overall care and support being given by the association has boosted their moral seeing the future positively and are optimistic to live long, to which the same populations accounted for 100 percent(see Table Below).

Table 4.1 Socio economic and demographic landscape of the sample population

Age group	Male	Female	Total
0 to 4 years	**5**	**20**	**25**
5to 9 years	**30**	**26**	**56**
10 to 14 years	**45**	**25**	**70**
15- to 19 years	**24**	**16**	**40**
20-24 years	**15**	**20**	**35**
25-29 years	**26**	**20**	**46**
30-34 years	**20**	**15**	**35**
35-39 years	**10**	**6**	**16**
40-44 years	**8**	**7**	**15**
45-49 years	**5**	**12**	**17**
50-54 years	**6**	**12**	**18**
55-59 years	**4**	**8**	**12**
60-64 years	**3**	**5**	**8**
65-69 years		**2**	**2**
70-74 years	-	-	-
75+	-	-	-

**Age ranges are directly taken form the CSA Standard

Source: Own study Survey Result, 2015

During the data collection, the necessary clarifications and explanations were given to respondents in order to build trust and confidence. Therefore, it has based been done alongside representatives of patients and closely monitored and carefully encoded, in order to avoid confusion and ambiguity at the later stage of data analysis. Accordingly, all distributed questionnaires schedules were filled out and were collected.

According the WHO principles, as indicated in second chapter of the study, the following are the major types of support for patients under the HBCS:

1. HIV voluntary counseling and testing;
2. Psychosocial support for PLWHA and their families and
3. Nutritional care.

4.2. Assessment of the Existing Services

In order to assess the care and support services made available to the beneficiaries project documents reviewed, interviews with the staff and beneficiaries representatives were conducted. According to the responses obtained, the care and support services available in MENA are organized under Home Based Care, Socio-economic support, Psychological support and legal assistances. Under the HBC, the care and support services rendered are medical and nursing care, psychological, socio economic, hygiene and massage service for bedridden patients, cereal flour provision for HIV/AIDS patients and malnourished orphans, preparing food for the sick and bedridden patients, medication and medicine cost coverage, detergent provision and ART provision and administration.

The Socioeconomic support which is usually preferred in the association to be termed as social support includes livelihood support like skill training, seed money provision for income generation scheme development, provision of money for housing rent coverage, school fee coverage, uniform provision for students, transportation fee support for college students, stationery provision, food distribution, support to establish PLWHA support groups and provision of night wears like blanket and bed sheet .

Respondents also mentioned that in the area of the psychological support MENA provides mainly posttest and ongoing counseling as emotional support and stress management for promoting living positively with HIV/AIDS. The counseling service conducted for individual, family, group and couples is the basis to meet the special needs and problems of each client setting. The other component of the Care and Support Program of MENA is organized to provide legal services. Under this support clients are receiving legal advice on their human rights, social life and services that address stigma and discriminations. Respondents mentioned that though the organization has a legal section there is minimal help they are getting from the organization.

In order to assess to what extent the Care and Support Program addresses the felt needs of the client, key informants were asked to identify the felt needs of PLHA and orphans and the most needy persons for care and support program along with their level of satisfaction. Before identifying the needs of HIV infected and affected persons, participants pointed out that as we members of this association are poor and destitute our problems are many and have no ends. As to the problem or need of PLHA and orphans, exhaustive lists were mentioned by the discussants. From these the most basic and burning ones as per the respondents' sense are:

- Meaningful protection and support from the community
- Legal support particularly from woreda administration to properly deal with stigma and discrimination, violations of human rights, inheritance rights of children upon the death of parents, inheritance rights of women upon the death of their husband, etc. The felt needs mentioned include
- House rent coverage
- Nutritious food support for those taking ART and for those recommended to start ART
- Special attention and service provision for orphans living with the virus
- Meaningful awareness raising in the community about HIV/AIDS and PLHA

Besides these, most essential needs mentioned by the respondents under each service category are: **psychological support** counseling and follow up of orphans' emotional

problems, **socioeconomic support** skill training, income generation programs, creation of work for able bodied PLHA, incentives for those PLHA providing awareness education in public, education for orphans, and children from chronically ill or bed ridden parents, house rent coverage for the economically poor, proper attention and closer follow up of those who were given training or establishment fund to start income generation projects, food, awareness raising on HIV/AIDS at family level, **medical** walking aids to persons with disabilities, ART, clinical and medicine provision, reproductive and life skill training, and **legal support** special protection for those PLWHA providing awareness education in public to address stigma and discrimination and violation of other rights.

Following the awareness of the needs and problems of PLHA and orphans, key informants were asked to point out the right beneficiaries to the different care and support programs of MENA. Before identifying the beneficiaries the respondents suggested that prior to giving access for any kind of socioeconomic help a detailed investigation has to be undertaken whether the client has any reliable economic sources or support or his/her potential to work.

They also suggested that assessment should be done with the participation of PLHA, community, woreda and MENA officials. If the assessment result proved the client has no economic source and unable to work he/she should be helped as per their interest. For those who can work training need to be given or establishment fund provided so as to meaningfully enable them to start self sufficient life depending on the availability of fund. They further suggested of the financial and material supports need to be handed based on the joint assessment of the aforementioned group. Medical support is also said to be given with this notion. Human rights, legal support and psychological support should be open to all without assessing the client's socioeconomic status as discrimination, marginalization and different forms of rights violations exist in the community.

In connection with the interview of beneficiaries and their entitlement to the home based care and support provisions key informants uncovered that MENA gives priority to socio economic support for physically weak and bedridden patients. They said that this kind of

notion is totally jeopardizing all the best deeds of the organization. This was properly expressed in the beneficiaries interview as those who are youngsters and seems strong enough to work and who are automatically rejected from the socioeconomic supports feel they are underserved. The interview conducted with the MENA official confirmed that selection is undertaken by technical staff of the association however, he added the association in principle accepts that all members of the association has the right to get this services but due to budget constraints all are not given the services.

To access the most needy ones the association set criteria based on health condition, economic status, age and academic standard. In any of the criteria the clients will be selected if he/she proved to be economically poorest of the poor as most of the members of the association come from economically poor segment of the population. In relation to the duration of the assistance, the official said that clients who qualify for the support get the service till their case improves but this depends on the availability of fund and resources.

Respondents pointed out that if people who seem externally strong and healthy but internally weak ones do not get this support at earlier times. Due to this fact, in a short period of time end up chronically ill and bedridden ones. Therefore, to keep them strong and enable to live on their efforts the socioeconomic support should be given as early as possible before they get weak.

It is also indicated that orphan children are not given special attention as they are Vulnerable to many forms of abuse and neglect. AIDS orphans, particularly double orphans are said to be among the neediest groups for the care and support program of MENA.

4.3 Practices of Medical and Nursing Activities

The approach to the HBCS intervention has been in line with the WHO standard of, firstly identifying HIV/AIDS patients through proper medical diagnosis. Accordingly, each patient respondent has submitted his/her medical certificate MENA at the early stage of providing help and support. It is true that under the HBCS, nurses are the most

important components of the overall process, given their close and regular medical, psychological, nutritional, sanitation etc. services to patients. Hence, nurses are expected to provide patients with regular medical support that may include injection, dressing and monitoring quinines are taken as per prescriptions.

However, half (52 percent) of the respondents confirm that nurses are coming regularly and provide patients with medical support at home. And 40 percent of the respondents attest that nurses come without complete medication. With same string of issue of ensuring that patients are properly taking medications as per prescription, respondents that confirm that nurses are making regular follow-up accounted 53.3 percent. ART provision is the most common form of medical support to PLHA in many parts of the country. It is true of patents under MENA's HBCS programme that three quarters of the respondents (76 percent) confirm that patients are getting ART (Survey Result 2015). Form the interview given by MENA's HSBC project coordinator, it was learned that, the clients or patients are grouped in two three categories of PLHA (People Living with HIV/AIDS), OVC (Orphans and Vulnerable Children) and MARPs and rendering the care and support activities without any discrimination of the ascribed status. However, it is to be noted that the Medical and Nursing care and support is given in MENA's own clinic and specially HBCS -trained medical staff are performing both the medical and psychological support and including the VCT according to the ethical and professionals norms to patients(Ibid) .

Table 4.2 MENA's Medical and Nursing Services as perceived by patient respondents

No.	Questions	Strongly Disagree	%	Agree	%	Neither Agree nor Disagree	%	Agree	%	Strongly Disagree	%	%
2.2.4	Caregivers are providing regular medical support (injection, dressing to the patients)at home	15	20	0	0	15	20	25	33.3	20	26.7	100
2.2.5	Nurses are coming with the necessary medications	30	40	0	0	16	21.3	18	24	10	13.33	100
2.2.6	Caregivers regularly make sure that patients take their medications properly	11	14.7	0	0	7	9.3	17	22.6	40	53.3	100
2.2.7	MENA regularly provides ART to PLHIV/AIDS	9	12	5	6.7	0	0	4	5.3	57	76	100

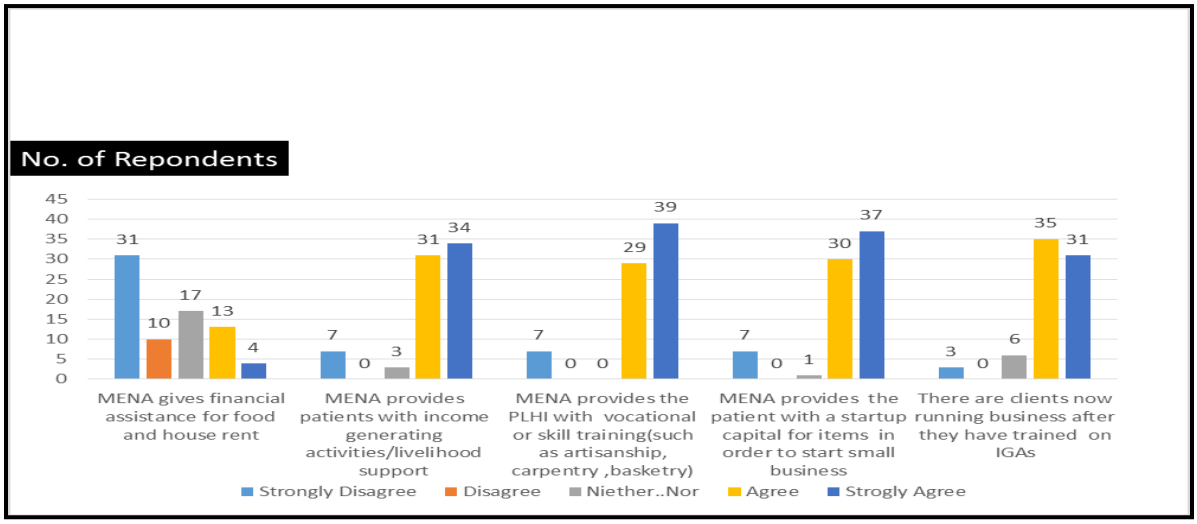
Source: Own study survey result, 2015

4.4. Socio-Economic Support

The socio-economic support under the HBCS is needed to enable patients economically self-supportive through a limited financial assistance. The most common practice is that, at the first stage patients are given some amount of money for basic household expenses such to buy food and clothing items and for house rent. At the later stage, some finical grants are given to then patients, so that they can start small business. From such a grant patients will engage in many income generating activities after awhile they will be graduated to ensure sustainable economic base at their household level. 93.3 percent of the respondents have confirmed the patients are being given seed money to start small business, purchase hand tools, as part graduating them from long-term economic dependency.

Form the diagram, below, one can infer that the need for food and nutritional support still persists. The food assistance is found to be more important for the patients or other may

infer that the priorities of the patients is to by a food item they prefer than receiving the ration.



Source: Own study survey result, 2015

Figure 4.1 Comparative Socio-Economic Support Provisions

4.5. Support for Adults and Children Affected by the HIVAIDS

During the study survey its was found that children under supported the HBCS program take two forms. That are those who live with their biological parents and those who lost their parents to the HIVAIDS and living under the guardianship of their closes relatives. Children are the other segment of HBCS programme. 40 respondents (53.3percent) of the study population confirmed that their children are provided with food items such as flour, bars of soap etc. However a separate food staff (enriched with vitamins and minerals) has been rationed for their children.

68 percent of "parents" of the orphaned children have also attested that they adopted children are being treated the same in terms of nutritional support with those who live with their biological parents. The same is true for all children who study in local primary schools that they are provided with exercise books, pens, pencils, backpacks, schools uniforms (Survey Result 2015).

4.6 Psychological Support

Under the HBCS support approach, patients are to be provided with Psychological Support in addition to the economic one. The psychological rehabilitation to the patients is paramount importance in addition to the financial support. One of the common mechanisms is to employ counseling services and promoting voluntary testing. The psychological support is also aimed at boosting the morals of the patients so that they became self-reliant, productive and psychological stable against the social stigmatization and a sense of dependency. The same support 68 percent of the respondents are getting professional counseling by nurses. It was found out that the same numbers of respondent are also holding discussions freely their homestead. It was identified that 6 out of the 7 caregivers patients are making regular visits for counseling and psychological support accompanies by sharing their own experiences and inter feeling to achieve trust and solidarity with their patient. The same percentage has also indicated that have also added that it is through winning the confidences and trust of patients the HBCS becomes a possibility.

MENA's innovative approach here, has be shared to other HBCS centers in the country is that the adopting of the existing traditional social practice to promote the psychological support. 70.6 percent of the respondents confirmed the occasional coffee ceremonies, where patients com and sit in round chatting many issues surrounding the care and support. Therefore, nurses make use of these harmonious gathering for counseling, educating, and other importance issues. During the conduct of discussions under coffee ceremony, it was found out 90.7 percent of respondents replied that nurses are not encouraging patients to be free and relaxed in terms of sharing their preferred stories and feeling but also their inner felling to caregivers (Survey Result 2015) . According to the accounts of MENA's HBCS Project Coordinator, the HBCS process is being undertaken in line with global operating procedures and HAPPCO working guidelines. Patients are provided with medical care and psychological supports based on the assessments and recommendations of health professionals. But other supports are given depending on the duration of the project and availability of funds. For example, those who need ART are provided, that is free of charge.

4.7. Monitoring and Evaluation

Patients have the notion of the HBCS: This part of the analysis tries to make an assessment outside of the basic principles of the HBCS in the study area. However, it deals with the general understanding of as to how the supports and services rendered to patents have contributed for sustainable livelihood.

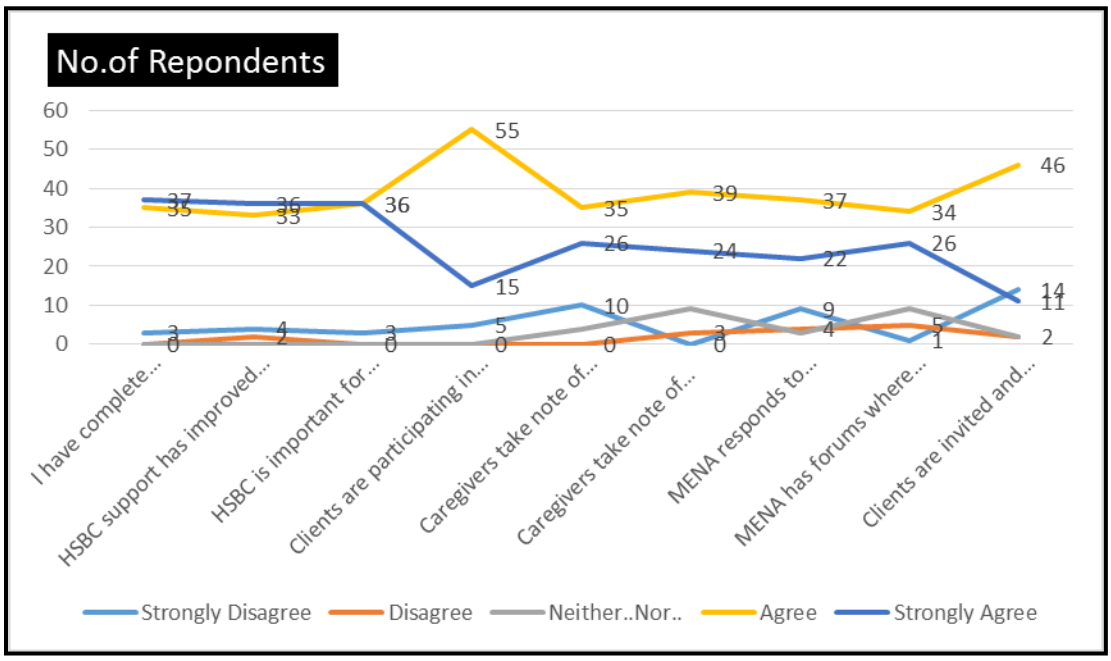
Therefore, an attempt was made, if patients have an understanding of the HBCS program, the contribution of care and support to their long –term livelihood. According to MENA's HBCS project coordinator, Mr.Sisay Edecha, it is from the start that new coming patients are always given briefings on the purpose of the HBCS, objectives of the care and support services as well as the short and long-term goals while being taken under the project. Afterwards, patients are voluntarily fill out formats to express their consent to go under the HBCS scheme.

A triangulating questionnaire has also been developed for patients on the same point of discussion. Accordingly, 73.3 percent of the respondents said that they understand the overall purpose, the types of service and support.

Sustainability of Care and Support: it is true that MENA has provided patients with startup capital or seed money in order to help them start their own small business and other income generating activities. To the same purpose the study has attempted to understand whether patients have succeeded to date in running businesses. To this fact, 88 percent of the sample population has attested that patients are at present actively engaged in various forms of income generating activities and supporting their livelihood. It was also found out that some patients are running their won small business independently and to the extent they have graduated to saving .Therefore, a conclusion can be drawn the socio-economic support has proved to be functional given 92 percent of patient respondents have concluded the fact (Own Survey Result 2015).

As to how tangible change in the lives of the patients have been achieved so far, the study has found from the coconuts of caregivers that patients that were bed-ridden have recovered and presently they have become self-reliant and contributing in terms of

counseling and rehabilitating activities in the project. The same fact has been corroborated by Caregivers, that some patients are performing counseling and other rehabilitation activities to fellow needy patients in their neighborhood, treating and comforting other patients in bed. They have developed a profound altitudinal change



Source: Own study survey result, 2015

Figure 4.2 Assessment of MENA's Performance on the HSBC

Form the graphic description, above suggest that the overall care support activities of HBCS by MENA is found to more pronounced than (see the Agree(yellow) line of data trend) More quantitatively, the result shows that 96 percent of the same population has confirmed that caregivers are also said to have been making regular visits to patients for counseling. The participatory nature of the project involving patients has also been tested with the view to understand patients are developing a sense of ownership of the process. Accordingly, 80 percent and 76 percent of the target population said that MENA invite them that they participate in various forums involving local government agencies, health professionals and other stakeholders and in the annual meetings of meetings of MENA, where performance reports are heard respectively. All respondents (100percent) have are

involved in cross-counseling both at home and in neighborhoods. Such a paradigm change in attitude, he added that would contribute to the effort in reducing infection rate. The same is also true that caregivers have also attested that they witness tangible emotional and behavioral betterment in their patients

Handling of feedbacks, complaints and enquiries are believed to be important mechanism as part of achieving durable change in the lives of the patients so that 81.3,84 and 78.7 percent of respondents have conceded that it the same has been true. From interview given to the Project Coordinator, as to who the Monitoring and Evaluation has been practiced, he responded that MENA has its own Monitoring and Evaluation and Department, with proper framework to make periodic assessments and corrective measures as per feedbacks and lessons gained through involving both patients and the operational staff.

Generally, all respondents agree that MENA is providing all the supports that are globally established. They have listed they are getting medical economical, nutritional (limited) and psychological care and support including training and transport allowances. The Project Coordinator has also added that MENA also provide other forms of support such as providing legal and liaison services to process legal requirements of HIV/AIDS orphans and other helpless and vulnerable patients with pertinent local government agencies and other stakeholders (Study Survey, 2015).

4.8. Best Practices

Based on the objective of identifying the best experiences and practices there by creating access for other agencies to adapt and even to help MENA capitalize on it, interview with the beneficiaries. These uncovered that the following services and methods of operation are the best practices that need to be adapted and continued. The outstanding practices are:

- Provision of home based care services based on the felt needs of bed ridden PLHAs through professionals and volunteer PLHA.

- Provision of counseling both by professionals and PLHA in individual, group, family and couple base by integrating live experiences of PLHA and other pertinent groups.
- Establishment and closer support for PLHA support groups. These enabled clients to get peer support to feel with their problems, encouragement to live positively with the virus, to protect stigma and discrimination, to learn better ways of living, developing a sense of belongingness which further installs hope of having protection at critical times.
- Provision of services with professionals, volunteers (PLHA) who are committed and having determined vision to improve the living situation of persons infected and affected by HIV/AIDS.
- Creating opportunities for PLHA to share their life experiences which help to address problems that come because of the virus and looking alternative solutions that significantly contribute to make each day comfortable
- The use and follow-up of the nationally approved and accepted policies, guidelines, protocols and rules and regulations.
- The willingness and determination to accept and adapt new improvements and to make improvements on the existing interventions.
- The special attention given to follow the CD4 status of all PLHA and those needing
- ART.
- Establishment of emergency fund allocations to cover costs related to medical services.
- Working together with locality idirs to facilitate burials.
- Facilitation of appropriate opportunities and fertile grounds for staff, PLHA trainees and families on inter and intra group basis experience sharing programs.

CHPTER FIVE: SUMMARY, CONCLUSION AND SUGGESTIONS

5.1. Summary of Major Findings

As mentioned in the methodology section, a total of 83 subjects 75 beneficiaries, 7 care givers and 1 official from MENA were included in the study. Employing quantitative data sources, the study provided an assessment of the home based programs. This section discusses the major findings and presents conclusions, suggestions and recommendations made by the researcher.

Persons living with HIV/AIDS and orphans have wide – ranging needs. To address these needs, programs require the setting of standardized objectives. The documents reviewed revealed that the national care and support program guideline is designed in such a way so as to meet the globally recommended objectives set by WHO. Based on the national guideline MENA has adopted its objectives to render quality care and support services for PLHA and AIDS orphans. Setting such clear objectives that match with the local condition, availability of resources and demands of beneficiaries is found to be considered as laying a strong foundation and paving ways to offer quality services. The researcher found this as the initial strength of MENA that enables it to render the required home care and support services in such a resource constrained setting. However, the assessment indicated the existence of some constraints that hinder MENA not to attain the objectives as they are meant to be attained. This will be discussed in the subsequent sections.

The wide ranging needs of persons living with HIV/AIDS are categorized under four broad categories: medical support, socio-economic support, psychological support and legal and human right assistance (WHO, 2000).The document reviewed revealed that MENA has also organized its home based care and support services under four broad categories, found similar with the WHO classification. The only difference observed is the term given for medical/clinical care in MENA as Home Care. However, the services that exist are in line with the principle of WHO. This categorization implies that MENA's initiative to provide care and support services meets the global recommendations.

The close review of the project documents, interviews held with beneficiaries, care givers and with MENA official reveals that most of the activities categorized under the four major areas of care and support programs are found in MENA program. The effort to provide these supports appropriately is hampered by lack of human, technical and financial resources. In this regard, the care and support activities found in MENA are leveled under the intermediate complexity and/ or cost service delivery categorization of the WHO classification. Of course, some of the activities are also found unavailable to link all the care and support services as per the WHO standard in a continuum of service provisions. However, the effort of MENA to make available the essential care and support activities with the prevailing financial constraints was found as one of the indications for the strength of MENA's capacity and its endeavor in attaining the needs of beneficiaries.

As to the burning needs of PLHA and orphans, participants revealed that meaningful protection of human rights of people infected and affected by HIV/AIDS, legal supports by the woreda (local administration), housing assistance, and nutritious food support for those taking ART are the most essential needs. All around support for orphans and for children who came from severely sick parents is also mentioned as a priority need. The assessment concludes the overall program of care and support intervention of MENA is organized to address these needs. However, due to the resignation of the legal officer and the low level of awareness on HIV/AIDS in the community has shown some gap in meeting the legal assistance and protection needs of PLHA and orphans. This gap could also be attributed to the network MENA has with the local woreda administration. However, the case is crucial and needs further strengthening and improvement.

Regarding the stigma and discrimination they are facing, participants revealed that, PLHA and orphans have frequent change of houses to cope the problem. Also, due to their economic insufficiency, they are forced to look frequently for cheaper rent houses. Participants bitterly described that most of members of MENA are from the lower economic groups that face housing problems as the most burning and felt needs of all HIV/AIDS infected and affected persons. They further added MENA did not provide this assistance to all the neediest persons rather; it gives priority to bedridden patients.

Thus, what strengths are observed in other services, the primary data obtained reiterated that MENA falls short in meeting some of the basic needs. This could be attributed to the resource constraints in the association and the limited help the community has to persons infected and affected by HIV/AIDS. This, as to researcher's belief, needs further investigation and thus should be addressed as needed. Social workers in particular are expected to be involved in this kind of research and to play their role of advocacy on behalf of these underserved citizens.

Similar to the housing problems, all around support to orphans (including food, school, clothing, shelter and nutritious food for people taking antiretroviral therapy are the ones reported by those whose needs are not met . As children are the future assets of any country and as they are suffering from the impact of HIV/AIDS at earlier ages the situation calls for the determined actions of all concerned bodies. Similarly, ART is a recent intervention, where once it is started its interruption or giving up totally jeopardizes the whole intention of the program and particularly affects the beneficiaries. The absence of such proper service provisions in these two areas could not be taken as overlooking the importance of the services or lack of commitment by MENA. As the interview with MENA official revealed, this happens because of the financial constraints. Budget limitations to meet the needs of beneficiaries can easily be observed from the increase in the number of members of the association. Though the services are similar in their types and in their formative years, MENA showed the mismatch of the budget and the needs. With budget limitations, it is illogical to expect addressing wide ranging needs of beneficiaries. However, adequate effort by all concerned bodies is needed to change this blurred picture. Particularly, the government should play the leading role in mitigating this problem.

Participants also pointed out that in MENA there is no room for beneficiaries' participation at any stage of the project cycle. The participation of beneficiaries is a strong element to effect program implementation as well as identifying the key needs of the beneficiaries. As there is no single intervention or "magic bullet" to address the multifaceted problems of PLHA and orphans, meaningful participation of beneficiaries could critically help the success of MENA's initiative. However, the absence of involving

beneficiaries in the program forced them to consider MENA as an organization mainly gives priority for physically weak and bedridden patients and overlooks the magnitude of the problems in housing support, orphans support, nutrition support for ART groups. This attitude further was developed in the perceptions of clients of MENA that MENA has less commitment to support them with the needs until they become bedridden patients. This also reveals the absence of transparency in project implementation with respect to MENA. During the interview, participants showed greater interest to participate in their programs. Literatures also favor the greater involvement of PLHAs in HIV/AIDS interventions, which benefits both beneficiaries and implementing organization. This critically helps in attaining the goals and objectives of the program as well as in improving the life of the clients. The researcher takes this opportunity to mention to MENA that the willingness of beneficiaries is a greater asset that needs to be scaled up to improve services rendering mechanisms.

The large number of needy clients to support is mentioned now and then both by beneficiaries participated in the interview and by the official of the association. Due to funding limitations, the officer said, the association gives priority to address some of the needs of the beneficiaries who are in critical condition who are either unable to involve in any forms of income generating schemes, especially those who have severe economic problems. Adding

to this, he said, in principle, MENA is organized to support all PLHA and orphans to its level best with the existing resources. Interviews held with beneficiaries' care givers and MENA official revealed that MENA has an open door policy to all HIV/AIDS infected and affected persons in areas where it is functioning. The main reason described here is, as per the official point of view and from the initial motto of the association, accepting all applicants to membership enhances the establishment and strengthening of PLHA support groups.

This further helps member to share their problems, to learn from each other the positive ways of living with the virus, devise pertinent mechanisms to cope with their problems, help to fight the spread of the virus and to initiate others to have the HIV blood test and

to decide and take every relevant measures on time. He further added, this has lots of advantages that no one can list exhaustively. As described earlier, the shortage of fund could not enable MENA to help all the needy with their material and financial needs. The interview held has shown that most of the members of the association who came with deep rooted problems which were not addressed anywhere before they get in to MENA are enabled to have dramatic improvements. The improvements in their ways of life are evidenced in their responses mentioned in the finding section. Therefore, in the opinion the researcher, allowing membership by itself is showing acceptance of PLHAs. The feeling of acceptance will further help members to develop a sense of belongingness. By and large, MENA's principle of open door policy and provision of this service helped to improve the quality of life of people living with the virus and their family. In connection with the feelings of unaddressed economic and material support, MENA needs to increase the awareness of its members that its financial resources are frequently not in a sufficient position to address the material and financial needs of all needy members, though their case is concrete and acceptable. MENA also needs to communicate clearly the criteria set in identifying beneficiaries for the support.

The findings indicate that MENA uses trained and professional nurses and part time medical doctors to manage medical and clinical cases. The interview revealed that beneficiaries are very much satisfied with the services they get from this section. It is also mentioned that, the established procedure of reimbursing costs expended for purchase of medicine and inpatient services beyond improving their health help to develop a feeling that PLHAs have better concerns by others. This implies, the medical services provided in MENA help to improve the psychological makeup of the beneficiaries.

The interview with MENA official disclosed that there are about 101 trained volunteers, who work as home based care givers in the association. This group is improving the situations of the weak and bedridden patients. In the interview with beneficiaries', it is noted that though members have said priority is given to the bedridden patients the services given to this group is dramatically changing their bad situation. Almost all care givers who participated said being a HBC giver I have seen many bedridden patients who after receiving proper care have improved their situation and have come to help others.

All said there is nothing that makes them happy than improving the situation of a person. These all imply that people would have been dead if they are not given support on time. The home based care services are found crucial in changing the quality of life of PLHA. These activities are among the others that help MENA to meet its goals and objectives.

Participants, emphasizing the counseling they had from MENA, said if we had not had this counseling we might not get this chance to see each other. It is also mentioned that the existence of PLHA support groups and counselors who live with the virus helped all newcomers /members to get a living example that if any person accepts his/her serostatus can hopefully live positively with the virus being as an active citizen. This meaningful counseling that dramatically and significantly changing the bad situation of PLHAs should be taken as the most and the foundation of all strengths of MENA.

Regarding the work atmosphere interview conducted with beneficiaries' representatives noted that MENA has harmonious relationships between and among staff and beneficiaries. It is observed in MENA there exists persons with different sex and serostatus composition. Any sort of dysfunctional relation based on serostatus and/or sex or any other forms considered harmful and stumbling block for smooth running of overall programs of any organization. In MENA it is well confirmed from interview and observation that relations and the work atmosphere is very much encouraging. From social work point of view this harmonious relationship that exists between and among persons in MENA's compound is an important vehicle in MENA's effort for promoting, restoring, maintaining and enhancing the well being of PLHA, their families, and their member association and enhancing and strengthening its care and support activities via team sprit orientation.

The study also revealed beneficiaries have positive attitudes towards the overall home based care and support programs of MENA. Beneficiaries' mentioned that the bad situations of PLHAs improved right after they get membership status to MENA. To summarize this finding, MENA's home based care and support is improving the quality of life of PLHAs and orphans. Based on this finding, the most significant and crucial support for people infected with HIV/ADS is found to be installation of hope via

appropriate counseling and supports from PLHA support groups. In regard to this support, the researcher is confident enough to say if any PLHA sets his/her feet one step in to MENA's compound his/her psychosocial problems and worries will get improved and see his/her future with better hope and vision.

Though this assessment enabled to see MENA's intervention in improving the situations of the members of the association, subjects interviewed disclosed that it has some problems to render services that address some extent of the wide-ranging needs. The problems mainly arise from insufficiency of resources, the increasing number of needy clients, and absence of participating beneficiaries in the program and lack of strong networking. Since MENA is working in very scarce resource settings with large number of clients it is logical to expect the existence of plenty of unmet needs and complaints. The absence of meaningful beneficiaries' participation has made clients feel that comprehensive care and support of MENA mainly goes to the weak and bedridden ones. It is also mentioned most of the members take it for granted that being a member in MENA is considered an automatic entitlement for supports. These all implies that MENA lacks transparency in its activities and program implementation. Beneficiaries' participation is believed of a help in matching the existing scarce resources with the most needy ones and to avoid any misconceptions. It also helps them to cooperate with the status quo that could give room to look for their own alternatives.

One of the ways of improving service delivery is making timely monitoring and evaluation. Accepting the importance, WHO (2000) recommends organizations to allocate about 10 percent of the project budget for monitoring and evaluation activity. The review of document and interview with the official revealed, MENA allocated 7% of the budget for the purpose. However, no attempt is seen for its implementation. Conducting monitoring and evaluation using trained staff with the participation of stakeholders would have been a help to make timely improvements of interventions, identity achievements and best experiences, and show the public the gap between demands and supply. It also would help to make decisions on resource allocations, to prioritize needs and to gear interventions towards the full realization of goals and objectives of the association. This study uncovered the impotence of monitoring and

evaluation particularly for MENA to improve its intervention which directly contributes in improving the quality of life of its clients.

5.2. Conclusions

Mekidim Ethiopia National Association which was established in 1997 by persons who are infected with and affected by HIV/AIDS whose number at that time could not exceed the number of fingers in both hands of an individual has now exceeds 5000 members. By utilizing the national HIV/AIDS care and support policies, guidelines and strategies MENA, is rendering services to persons living with HIV/AIDS and AIDS orphans.

From the overall reading the study with the view to achieve the set objectives. Therefore, an attempt has be made to give a important and substantive information to the readership. It is true that MENA's area of specialty i.e., the HBCS is contributing a lot in terms of providing access to poor and helpless patients as well as the OVCs. The initiative and efforts made so far to the patients are encouraging

One can simply understand the importance and the contributions of HBCS in alleviating the economic, medical and psychological human and burden through providing care and support to the poor and helpless patients with minimal finical resource s. equally important, the positive impact in improving the lives patients. It is also true that HBCS would undoubtedly contribute to the relief of local health institutions known for their limited human and financial resources, in terms of reducing the number of patients that would go in search of the same care and supports. On the other hand the HBCS project plays an important role in promoting the culture of voluntarism for patients. The findings of the study have made possible to infer that caregivers are committed to help the needy.

Generally, MENA's HBSC program has achieved creating positive impact on the side of patients, giving rise to enable patients become, economically self-supportive, emotionally stable as well as developing hope and cooperative to fellow patients. Socially, it is possible suggest that the HIV/ AIDS related stigma against patients can be reduced that may come for the surrounding community through the HCBC program. The assessment

conducted here based on the principles of process evaluation concludes the following as a whole.

1. MENA has organized and categorized the basic care and support services and activities in line with the recommendations of World Health Organization which help to offer the required care and support services in a continuum.

2. The overall assessment of the care and support interventions of MENA found as improving the living situations of persons living with the virus and their families.

Specifically these improvements observed in:

- installation of hope on continuity of life via counseling and support of PLHA associations
- facilitation of obtaining supports from each other by organizing and assisting PLHA support groups
- provision of experience sharing opportunity among beneficiaries on living positively with the virus and learning different coping mechanisms for their problems
- restoration of the feelings of worth of an individual and human dignity via open door policy for MENA membership
- establishment and enhancement of functional interaction and peaceful work atmosphere
- improving the health and living situations of bedridden patients and homebound PLHAs via provision of professional homecare services and medical/clinical supports
- assisting PLHAs and orphans via the provision of transportation money and school supplies for those attending schools and higher educations
- provision and management of ART and CD4 follow up
- developing the feeling of belongingness and worth of an individual via the support they are getting on medical services like cost reimbursement

3. The assessment also identified the areas where MENA could not provide appropriate service or supports. The major areas that would have been addressed properly as per the continuum of care and support provisions are:

• the stigma and discriminations problems both orphans and PLHA are facing is not properly dealt with because of the low level awareness of the public and the loose network MENA has with the local woreda administration. Some of the draw backs in this intervention are attributed to failure in the central government

4. MENA also failed to give special consideration and attention on priority needs of beneficiaries. These needs include:

- housing rent coverage
- facilitation of interventions that address protection and support in the community with regard to the violations of rights and inheritances
- provision of all around support for orphan children
- provision of nutritious food for persons on Antiretroviral therapy

5. MENA has shown loose commitment in participating beneficiaries in project designing, implementation and monitoring and evaluation.

6. Beneficiaries have favorably perceived the services offered by MENA however some limitations and strengths are observed. The weaknesses of the organization include:

• absence of beneficiaries participation

• lack of commitment to effect monitoring and evaluation

• lack of establishing and effecting meaningful networking with the woreda and other relevant bodies

• absence of proper advocacy for attaining sufficient budget

• absence of transparency with service designing and implantation with

beneficiary's participation.

• absence of comprehensive support for orphan children

• absence of proper technique and mechanisms to identify the right beneficiaries with the right supports

The assessment found the following strengths of MENA:

• establishment of the association by persons infected and affected by HIV/AIDS and their initiation to help others

• attainment and adoption of the national HIV/AIDS care and support policies, guidelines and strategies with the local condition

• provision of counseling support

• establishment and strengthening of PLHA support group

• acceptance of all PLHA and orphans in membership

• establishment of conducive work environment and maintenance of functional relationships between and among staff and clients

• the patience and commitment staff has to support the large number of beneficiaries

7. From the overall assessment it is also possible to conclude that the services that MENA has significant budget constraints to provide comprehensive care and support services and hence MENA could not fully meet its goals and objectives.

5.3. Suggestion for Action

Based on the findings some suggestion could be pointed out for use both by MENA and other similar organizations as well as researchers who intend to pursue further and deeper studies.

As a whole, the home based care and support programs of MENA has made a significant contribution in improving the quality of life of PLHAs and orphans, via teaching living positively with the virus and enabling them to lead self sufficient. The lessons learnt from this are care and support intervention activities is that a single instance of assistance provided to PLHA and orphans has significant impact in changing the overall situations. Most importantly, the psychosocial support helps them to install hope and latter this hope urges them to look for the fulfillment of other needs that lead them to have self-reliable life. Therefore, as long as resources are available, the commitment in MENA can take all activities to a higher standard to achieve the goals and objectives to a better success.

The observed changes in the lives of PLHAs and the achievements of MENA indicated that if relevant measures are taken in MENA's care and support intervention modalities and improved financial resources, the observed changes would be have been scaled up to a higher level. Therefore, to improve the existing care and support provisions to bring significant and all rounded changes in the life of PLWHA and orphans the followings are recommended.

1. The lack of involvement or participation of PLHAs in the care and support provision of MENA led to misconceptions in the part of the members of the association. To change these erroneous understandings, to prioritize the needs of beneficiaries, to identify the most needy ones and above all to enhance the positive ways of implementing care and support programs, MENA should devise and implement meaningful and sensible beneficiaries participation in all project cycle.

2. One of the burning problems of PLHA and orphans found as legal support and attainment of human rights. This support is crucially needed from woreda and the community. With this regard, MENA should lay strong network with woreda and community based organizations like idirs, mahbers, religious associations, etc., to deal and assist PLHAs and orphans at all their legal support needs. Besides, MENA should also assign committed legal experts to

coordinate legal activities being a bridge between MENA and the community and to render proxy legal advice to the members.

3. It was found that the MENA has wide gap between the demands of clients and the funds availability that need to address the comprehensive care and support services particularly for socioeconomic supports. In order to minimize the observed gap and to address the needs of the clients, MENA has to look for better funding sources. To get reliable funding MENA has to work more on advocating its services and beneficiaries needs of supports to the public, community organizations, government, HIV/AIDS prevention and control offices and external donors.

4. The existing home based care and support services of MENA are proved to have a significant impact in changing the quality of life of beneficiaries and bringing concrete differences on those directly benefiting from the support. Therefore to extend the services to large number of needy clients and to improve also the existing interventions, MENA should scale up the already existing services by obtaining support from an increased number of funding organizations, increasing the number of volunteers and professional staff, sharing experiences from all directions, and increasing the public recognition of the support program.

5. Most of the problems observed in rendering the care and support services in this review and evaluation work is found to be attributed to the absence of timely and continuous monitoring and evaluation activity. Therefore, MENA is required to affect the planned monitoring and evaluation activities as per the adopted indicators of achievement, guideline and budget with the objective of improving the quality of service delivery. The findings of this evaluation came up with significant indications, fitting with MENA's plan of evaluation, that need to be utilized properly and to use as a stepping stone for effecting further evaluations in improving interventions.

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APPENDICES

Appendix A Interview Schedule for beneficiaries

Indira Gandhi National Open University (IGNOU)

School of Social Work

Part one

Interview Schedule for Beneficiary Respondents

Dear Respondent ,

My name is Yared Tesfaye, presently, and I am writing my MSW thesis in order to fulfill the requirements for the Degree of Mater's of Arts under the custody of School of Social Work of Indira Gandhi National Open University . The Social Work(MSW) thesis focuses 'Home-Based Care and Support Practices for People Living with HIV at Mekdim – Ethiopia National Association'. It is known that MENA' is one of the major organization that has specialized in the HBCS activities as its thematic focus of engagement.

Therefore, to achieve the study under testing, primary data are required as part of making the study more substantive and empirical. To this end I have formulated a set of questions of the interview schedule with the view to collect primary data on MENA's home-based care and support activities, in general and tangible achievements, challenges and completion in particular while undertaking the HBCs. The identity of respondents is kept confidential and will not be used for any other purposes what so ever, except this academic purpose. Thus, your genuine responses are vital for the study in order to arrive at an empirical finding wholly answer the study questions and address the objectives of the study.

*You agree to participate in the study. If yes, _____

Thank you!

I Profile *(Socio Economic and Demographic characteristics* **)**

Profile: (Social Economic Characteristic).

1. **Age**
2. **Gender**
3. **Head of the family**

   Male ☐ Female ☐

4. **Marital status?**

   1. Married ☐ Divorced ☐ Separated ☐ Never married ☐ Widowed ☐

5. **Occupation** : Daily labourer___ Micro business___ Masonry___
6. Other, please specify_____

5.1 Household average monthly income(ETB)

7. **What is the level of education of the head of the household?**

   1. Illiterate ☐
   2. Read and write ☐
   3. Primary School (1-8) ☐
   4. Secondary (9-12) ☐
   5. Higher (Above 12) ☐
   6. Other, please specify_____

8. What is your family (Household members who live under the same roof and share the same dish) family size by age group and sex including you?

Age group	**Male**	**Female**	**Total**
0 to 4 years			
5to 9 years			
10 to 14 years			
15- to 19 years			
20-24 years			
25-29 years			

30-34 years			
35-39 years			
40-44 years			
45-49 years			
50-54 years			
55-59 years			
60-64 years			
65-69 years			
70-74 years			
75+			

(CSA Standard)

9. What is the religion of the head of the household?
    1. Protestant ☐
    2. Orthodox ☐
    3. Muslim ☐
    4. Catholic ☐
    5. Traditional ☐
    6. Other, please specify_____
10. What type of dwelling you lives in?
    1. Iron roof with mud and wooden wall ☐
    2. Iron roof with mud and stone bricks wall ☐
    3. Other, (plastics, metal or iron sheet etc.)please specify___
11. Type of ownership to this dwelling
    1. Own house ☐
    2. Rented ☐
    3. Shared ☐
    4. Other, specify_____

11. Would you specify your ethnic group?_____(Using your father's line)
12. How did you know your HIV positive status

_____

13. How long have you been living with the IHV?

(1)Less than 12 months ☐ (2) Greater than or equal to 12 month ☐

14. How many intimate relatives and close friends do you have?_____relatives _____friends

15. Can you get the care and support whom you feel uncomfortable or are suffering from the disease flare-ups? (1) Yes ☐ (2) No ☐ (3) I cannot decide ☐

16. Do you believe that the available social supports have helped you for living long?

(1) Yes ☐ (2) No ☐

II Medical and Nursing care services provided								
2.1 Medical and Nursing care								
No	**Questions**	**Strongly Disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**	**Total**	**%**
1.2.1	MENA has established a clinic to the patients							
1.2.2	The clinic is equipped with the necessary equipment and treatment supplies							
1.2.3	The clinic has enough medical staff specially nurses for handling PLHA							
1.2.4	MENA is delivering HBCS to the satisfaction of the patients/clients							
1.2.5	MENA gives the necessary care and rehabilitation training							

2.2 Practice of Medical Nursing Activities								
No	**Questions**	**Strongly Disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**	**Total**	**%**
2.2.1	MENA does early identification of patients before the HBCS through health professionals							
2.2.2	Nurses provide clients with nutrition							
2.2.3	Nurses are coming with the necessary medical equipment and supplies							
2.2.4	Caregivers are providing regular medical support (injection, dressing to the patients)at home							
2.2.5	Nurses are coming with the necessary medications							
2.2.6	Caregivers regularly make sure that patients take their medications properly							
2.2.7	MENA regularly provides ART to PLHIV/AIDS							

No	Questions	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total	%
3.1.	MENA gives financial assistance for food and house rent							
3.2.	MENA provides patients with income generating activities/livelihood support							
3.3.	MENA provides the PLHA with vocational or skill training(such as artisanship, carpentry ,basketry)							
3.4.	MENA provides the patient with a startup capital for items in order to start small business							
3.5.	There are clients now running business after they have trained on IGAs							

4. Support for Adults and Children Affected by HIV/AIDS								
No	**Questions**	**Strongly Disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**	**Total**	**%**
4.1.	All children of patients get nutritional support and are at schools							
4.2.	MENA provides Orphans and vulnerable children with medical support							
4.3.	MENA provides orphans and vulnerable children with educational support (exercise book, pens ,pencils etc)							
4.4.	MENA provides orphans and vulnerable children with legal services for through legal professionals							

5. **Psychological Support**								
No	**Questions**	**Strongly Disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**	**Total**	**%**
5.1.	I and my partner freely express our feeling, during counseling							
5.1.	Caregivers do share their personal accounts of life in general							
5.2.	HBCS is important for HIV/AIDS patients because the Caregivers give counseling services on coffee ceremony							
5.3.	I share my inner feelings and secretes with care givers that I would not share to medical staffs in the hospitals and clinics							
5.4.	Caregivers are flexible and use changing their mode of counseling services in line with the need of patients							
5.5.	MENA provides PLHA with income generating scheme							
5.6.	My husband/wife supports me to participate in the HBCS programme							
5.7.	Further discussions about HIV/AIDS issues are being held in my household							

6. Monitoring and Evaluation

No	Questions	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total	%
6.1.	I have complete understanding on HIV/AIDS preventive and care .							
6.2.	HSBC support has improved my life (socially and economically)							
6.3.	HSBC is important for HIV/AIDS patients because the Caregivers give counseling regularly							
6.1.	Clients are participating in various committees in the HBCS process							
6.2.	Caregivers take note of inquiries and feedbacks of clients							
6.3.	Caregivers take note of inquiries and complaints of the clients							
6.5.	MENA responds to inquiries and complaints or feedbacks directly to clients							
6.6.	MENA has forums where clients, health professionals ,local government agencies and other stakeholders make discussions							
6.7.	Clients are invited and participated in quarterly/bi and annual meetings to hear performance reports of the MENA							

III Suggestions for Improving the Social Work Practice

1) What types of support you are getting from MENA?

i. ……..
ii. …….
iii. ……
iv. ……

2) Which of the support you have got from the Association most important for you?

……

3) What are the challenges you are facing while receiving the HBCS?

i. ……..
ii. …….
iii. ……
iv. ……

4) What real changes have you gained as the result of the care and support from MENA's HSBC project intervention? please describe them in order of importance

i. ……
ii. ……
iii. ……
iv. ……
v. ……
vi. ……...
vii. ……

5. What should be done on the part of each stakeholder so that MENA's HSBC can incorporate in the future project in terms economic, education support counseling, etc?

i. .....
ii. .....
iii. .....

5) What do suggest that should more should be done in terms of psychological support in the future?

i. .....
ii. .....
iii. .....

6) What do you think that should be done more to adults and children in the future?

i. .....
ii. .....
iii. .....

7) What you are the constraints that you want to be corrected in the future ?

i. .....
ii. .....
iii. .....

8) What should be done to promote the overall HBCS programme in the future?

i. .....
ii. .....
iii. .....

Thank you!

……///……

APPENDIX B Interview Schedule for MENA officials

Interview Guide with MENA Official

Questionnaire for MENA HSBC Project Officer/Coordinator

Dear Respondent ,

The purpose of this questionnaires is to make an assessment over activities of HBCS by MENA in general and tangible changes achieved in the lives of patients in the pre and post HBCS intervention in particular. The identity of respondents is kept confidential and will not be used for any other purposes what so ever. So you genuine responses are vital for the study in order to arrive at an empirical finding.

The study is conducted to the partial fulfillment of the Degree of Master of Arts under the custody School of Social Work of Indira Gandhi National Open University

Thank you

Interview questions

1. **Organization's programs and services**

1.1. What are the basic services which exist in the Association for PLHA and orphans?

1.2. Who receives them?

1.3. In what condition?

1.4. For how long?

1.5. Are the services consistent with the goals and objectives of the program?

1.6. What standards for quality of services have been established?

1.7. How do you express the communication patterns between management? Supervisors, and line staff influences services?

2. Voluntary Counseling and Testing

2.1. Does MENA provide VCT to all beneficiaries who are in need of the service?

2.2. How well do counselors meet clients' needs?

2.3. How do you assess the Association's capacity and condition to provide basic HIV Counseling and testing to manage HIV/AIDS clinical services?

3. Clinical Services & Management

3.1. Are there trained staff to manage HIV-related illnesses?

3.2. Are there trained staff to manage referrals for HIV-infected patients, and supervise palliative care?

3.3. What health facilities exist that have the capacity and conditions to provide advanced HIV/AIDS clinical and psychosocial support services including monitoring of antiretroviral combination therapy?

4. Supports

4.1. Are there volunteers in home-based care program able to provide full range of activities as per homecare manual or protocol?

4.2. Are there households in home-based care program who do not receive full range of locally-agreed home care activities?

5. Client population and referral sources

5.1. What type of client groups does this association serve?

5.2. Are any clients groups underserved or refused by the association (i.e., poor, elderly, women, persons with disabilities, gays/lesbians, or other vulnerable groups)?

5.3. How does this occur?

5.4. All people living with HIV/ADS require a range of care and support of services. Depending on the stage of this infection and psychosocial needs what referral system exists in the association to meet the felt needs of the person as indicated in HIV/ADS care continuum?

5.5. Have you also assessed the process of this referral?

6. Monitoring and Evaluation

6.1. How is Monitoring and evaluation planed and designed?

6.2. How often is Monitoring and evaluation taken? How often reports prepared periodically?

6.3. How much percent of budget from the total project budget allocated for monitoring and evaluation?

6.4. Are there locally adapted Monitoring and Evaluation indicators and instruments for data collection and analysis?

6.5. Is there any assistance by the government to enhance the capacity of MENA in Monitoring and Evaluation of care and support program?

6.6. Is there a way of communicating Monitoring and evaluation results to stakeholders, policy makers, beneficiaries, community members and program participants?

7. Miscellaneous

7.1. Which of the national HIV policies, strategies and guide lines applied by MENA and specifically which areas of the following covered in the program of care support?

7.2. What are the strengths and limitations of the care and support programs of MENA?

7.3. What outcomes observed because of this program?

7.4. Does the care and support program make a difference?

7.5. What are these differences?

7.6. To the best of your knowledge, what challenges is the above HBCS program facing?

Thank You!

APPENDIX C Interview Schedule for Caregivers

Part one

Interview Schedule for Caregivers

Dear Respondent ,

My name is Yared Tesfaye, presently, and I am writing my MSW thesis in order to fulfill the requirements for the Degree of Mater's of Arts under the custody of School of Social Work of Indira Gandhi National Open University . The Social Work (MSW) thesis focuses 'Home-Based Care and Support Practices for People Living with HIV at Mekdim – Ethiopia National Association'. It is known that MENA' is one of the major organization that has specialized in the HBCS activities as its thematic focus of engagement.

Therefore, to achieve the study under testing, primary data are required as part of making the study more substantive and empirical. To this end I have formulated a set of questions of the interview schedule with the view to collect primary data on MENA's home-based care and support activities, in general and tangible achievements, challenges and completion in particular while undertaking the HBCs. The identity of respondents is kept confidential and will not be used for any other purposes what so ever, except this academic purpose. Thus, your genuine responses are vital for the study in order to arrive at an empirical finding wholly answer the study questions and address the objectives of the study.

*You agree to participate in the study. If yes, _____

Thank you!

Respondents'' Profile:

Age……Sex:……Education Level .....

No.	Questions	Agree	Disagree	Neither /Nor	Strongly disagree	Strongly agree	%
1.	HSBC is important for HIVAIDS patients						
2.	I have complete understanding of the HIV/AIDS preventive and care methods .						
3.	I am happy in working in the HBCS program						
4.	Caregivers give counseling regularly						
5.	Patients freely express their feeling in during counseling						
6.	Caregivers do share their personal accounts of life in general						
7.	HSBC support has improved patients' life (socially and conically)						

8.	Patients express their inner feelings and secretes that they would not to share to Medical Staffs in hospitals and clinics						
9.	Caregivers are flexible and use changing their mode of counseling in line with the need of patients						
9.	MENA provides Income generating scheme to patients						
10.	MENA provides continuous training to caregivers						

Please read carefully the questions below and respond the same accordingly

1) What are the types of support MENA is providing patients with?

- ……..……..
- ……...…….
- ……
- ……
- ……
- ……
- ……

2) In which of the support are you involved most?

……

3) Are there tangible changes you have witnessed in the lives of patients as the result of the care and support from MENA's HSBC project in terms therapy? please describe them in order of importance

- .....
- .....
- .....

4) Are there real changes you have witnessed as the result of the care and support from MENA's HSBC project in terms counseling? Please describe them in order of importance.

- …….....
- …….
- …….....

5) What you are the weaknesses of the HBCS that you want to be corrected in the future?

- …….
- …….
- …….
- …….
- .....

6) What should be done in the future to promote the HBCS program to other parts of the country?

- ……
- .....
- .....

APPENDIX D Observation Tools

1. Home visits

Homes of Five home care beneficiaries visit to assess their situation with regard to:

• Material supports

• Use of assistances

• Integrations in the neighborhood (psychosocial and legal rights attainment)

2. Service/support provision observation

• Physically existing services/supports

• Clinical care

• Psychological support

• Socioeconomic support

• Human rights and legal support

• Participation of the beneficiaries in planning and delivering services.

3. Interactions and integration

In all the data collection times and methods participant and non participant observation will be made to look

• Free interaction of the beneficiaries among themselves and with the organization

• Treatment and handling of the beneficiaries with respect to human rights and legal needs

Thank you

……///……

PROFORMA FOR SUBMISSION OF MSW PROJECT PROPOSAL FOR APPROVAL FROM ACADEMIC COUNSELLOR AT STUDAY CENTER

Enrolment no: Id1115141

Date of submission: November 2014

Name of the study center: St' Mary's university

Name of the guide: Mr. Sebsib Belay

TITLE OF THE PROJECT: *ASSESSMENT ON CARE AND SUPPORT PROGRAM FOR INFECTED AND AFFECTED PEOPLE WITH HIV/AIDS AT MEKDEM ETHIOPIA NATIONAL ASSOCIATION IN ADDIS ABABA ETHIOPIA*

Signature of the student

Approved /not approved

Signature:

Name of guide: Mr. Sebsib Belay

Address: b.meye@yahoo.com

Name of the student: Yared Tesfaye

Address: Secretad99@yahoo.com

Assessment on the Home based Care and Support Programme for Infected and Affected People with HIV/AIDS at Mekdem Ethiopia National Association in Addis Ababa, Ethiopia

MSW Dissertation Research Project Proposal
(MSWP-01)

Yared Tesfaye Wolde
Enrollment No. ID 1115141

Project supervisor:
Sebsib Belay (Mr.)

Indira Gandhi National Open University
School of Social Work

November 2014
Addis Ababa, Ethiopia

Table of Contents

Contents **Pages**

1.1 Introduction

HIV/AIDS in one of the powerful killer epidemics of our times. Currently, since the start of the pandemic, some thirty years ago, our world has now become a home for about 35 million people living with HIV(UNAIDS,2014).However, the engulfing infection at a global scale has been on the rise and unabated from the past . In response, there has been unilateral and coordinated effort exerted both by individual countries and the international level. The continued global effort has now resulted in the sharp decline in terms of infection and transmission of the virus. According to the MGDs 2011 Report, currently, the number of new HIV (Human Immunodeficiency Virus) infections is 1.2 to 1.4 per 100 adults(aged 15 to 49)(UNAIDS 2013). . Southern Africa and Central Africa, the two regions with the highest incidence, saw sharp declines of 48 per cent and 54 per cent, respectively. It should be noted that, still, there were an estimated 2.3 million cases of people of all ages newly infected and 1.6 million deaths from AIDS-related causes. Sub-Saharan Africa was the region where 70 percent—1.6 million cases of the estimated number of new infections in 2012 occurred. (UNDP 2014)

Ethiopia is no different from this global pandemic with its prevalence and alarming spread which evolved from two cases in 1986, is spreading alarmingly and infected 1,475,000 (658,000 males and 817,000 females) people in the country (Ministry of Health , 2004 fact sheet). Despite the encouraging improvements in the process of combating the crisis of the epidemic, studies show that the challenge still persists and more to be done in the race to achieve the desired results. For example, the 2014 Human Development Report has put Ethiopia's prevalence rate at 47.2 percent

HIV/AIDS is more pronounced in adult age groups (15-49) According to the UNAIDS (2013) the highest number of HIV infected segment of the Ethiopian population (540,000 - 670,000) are in this age group. As this age group of persons are the economically active, the social and economic basis of the family and the society their death leaves the country with long lasting development problems. One of the worst impacts is leaving many children without parents (MOH, 1998). Before AIDS, about 2% of all children in developing countries were orphans1 but in 15 years from the first identification of AIDS

the number skyrocketed to 7% - 11% in African countries (Microsoft Encarta) 15–17% (Deininger, et al., 2003). And ninety five per cent of children orphaned by the pandemic live in this continent (Save the Children UK, 2001)

In order to contain the spread of HIVAIDS there have been several conventional and globally accepted practices aimed at mitigating the spread of HIV/AIDS such as ART provision, condom distribution, voluntary testing and counseling. The HBCS Home-Based Care and Support is another approach to the same effort.

According to the Joint United Nations Program on HIV/AIDS Report, Ethiopia is one of the seven countries – together with Botswana, Ghana, Malawi, Namibia, South Africa, and Zambia – showing a rapid decline by 50% or more. The report has emphases the role of HBCS to have played an indispensable role for the benefit of the majority of the population- in rural parts of those countries (UNAIDS 2015).

The HBCS is one of the recently employed preventive mechanisms as an alternative approach to that of the conventional approach called the Institution-Based Care and Support (IBCS). Nowadays its popularity is growing and many poor countries are practicing an effort to contain both the spread and prevalence of the killer virus in many developing countries, notably in many poor African countries such as Uganda ,Botswana, South Africa and Zimbabwe (HIV/AIDS Country Progress Report, Uganda; 2013). This approach is preferred by many poor countries for its range of advantages in terms economic and convenience. Firstly, it enables the poor that cannot afford for treatment and transportation long distance to reach health institutions. Secondly, it curbs the burden on health institutions with limited financial, material and human resources. The major features of the HBCS are that it involves little costly activities but largely human interaction between the care and support providers and the HIVAIDS patients and training at a community level.

From the facts above one can easily understand that that HBCS is an approach the most preferable and convenient for providing the necessary care support at patients' homestead one hand and the burden of costs for transportation, treatment, accommodation, etc where health institutions are largely located in urban areas on the

other. The other twin advantage of the HBCS is also for its contribution in minimizing the bourdons on health intuition, where the available resources are meager (HAPCO)

Definition of Concepts

The Home –Based Care and Support (HBC) also called Community-Based Care and Support (CBCS) is defined as

> The provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death. Home care services can be classified into preventive, primitive, therapeutic, rehabilitative, long-term maintenance and palliative care categories. (WHO, 2000).

Caregivers

> Refers to people such as families, caregivers from the formal system e.g. Professionals, caregivers from the non-formal system e.g. NGOs, CBOs. DPOs, caregivers from the informal system e.g. community health worker (CHW), volunteers, other community caregivers and church groups (HAPCO National guideline on home-based care / community-based care, 2000).

Clients (patients or the program is assist)

> Refers to individuals who need basic support services to continue to live and/or die in their community and without which they would have been prematurely, inappropriately or unavoidably moved to institutional care. This group of people may include healthy people, at risk or frail older persons, moderate to severe functional disabilities,, people recovering from illness, in need of assistance e.g. post deliveries or after specific treatment, terminally ill persons,,

persons living with HIV/AIDS or any other, debilitating disease and/or conditions e.g. mental illness, substance abusers and any other disadvantaged group/person in need of care and support (HAPCO National guideline on home-based care / community-based care,2000),.

Formal System

Are health institutions such as hospitals, clinics, health posts etc (Ibid).

Non-Formal System

Are institutions or organizations that plan, and extend care to clients .these institutions may include NGOs,, CBOs, FBOs and traditional healers and leaders (Ibid).

Formal caregivers

May include medical professional such as physicians, nurses, health officers etc that provide care and support to clients (WHO, 2000)

Informal caregivers

Are people community health worker (CHW), volunteers, other community caregivers and church groups (WHO, 2000).

HBCS is not intended to mean “second class care” or “cheap care” for those who cannot afford hospital care. For commonly occurring diseases/conditions can be effectively managed at home (WHO, 2000).

Institution -Based are and Support (IBCS)

Treatments being given to clients under formal institutions such as hospitals, clinics, etc (HAPCO National guideline on home-base care / community-based care, 2000).

Palliative care

Is a philosophy of care which combines a range of therapies with the aim of achieving the best quality of life for patients (and their families) who are suffering from life-threatening and ultimately incurable illness. Central to this philosophy is the belief that everyone has a right to be treated and to die, with dignity, and that the relief of pain - physical, emotional, spiritual, social - is a human right and essential to this process (UNAIDS, 2003).

Operational Definition of Home –Based Care and Support

The study has tried to define the HBCS in such a way that it fits in to both the international practices and Ethiopian realities on the ground in general and the approaches and methodologies of Mekdim Ethiopia in particular.

Therefore For the purpose of this particular study, the HBCS is defined as a set of medical, psychological and economical care and support given to helpless HIV/AIDS petitioners by the community within a community.

Interventions in Addressing the Problem

So far, there are several mechanisms employed to deal with the effects of HIVAIDS in many countries. Institution –based treatment, preventive education and training, ARV dug distribution etc are the most common approaches practice for many years, however, the Home-Based Care and Support, has been devised as an effective and economic

alternative mechanism. Since its introduction in 2000, many countries have adopted it in their national policies, strategies to combat the pandemic.

According to the 2012/2013 Annual Performance Report by the MoH, in Ethiopia, in fact there are positive changes in terms of an increase the number of PLWHA over the last nine years with combination of sustained prevention and increased ART coverage. As a result, the number of new infections has dropped. For example, between 2004 and 2005 EC for PLWHA ever enrolled in HIV/AIDS care has increased from about 667,000 to 744,000 that was only not more than 190 some nine years back respectively. The same is true for the number of patients that are actually getting care and support under the HBCS. The Report indicated under the same period from close to 275,000 to 309,000.

The need to conduct this particular study on the topic under discussion is initiated as part of making empirical contribution to the debate over combating the spread of the HIVAIDS in the country. Equally important, the H/CBCS is economically efficient to poor countries in the way that resources deemed to necessary to institution -based treatment could be put to other important efforts. From psychological point of view, it is largely under the HBCS that HIVAIDS patients enjoy freedom to express their inner feeling and emotions to the caregivers since the Ethiopian society are largely shay and refrain their inner most feeling to medical personnel in health institutions. In other words, the HBCS allows to build trust between patients and caregivers in the process where, the day-to-day livelihood of patients is shared and to which local councils and trainings are delivered informal social gathering such as coffee ceremony, other cultural and religious events.

It also be noted that currently, there are few NGOs directly engaged in the HBCS activities are located in towns and cities. At this point of discussion one can understand that more to be done in this regard in the face of the volume of patients the growing rated of prevalence at the national level. Therefore, it is with this set of mind and a strong belief that such useful preventive mechanism must be promoted and scaled up to the rest the country where fellow patients that have denied access to care and support can get the service within their reach. Good practices, challenges and other innovations form the HBCS process can be shred through proper research uptakes. So is the major driving

force that generated the motivation to undertake this particular study under the topic under question through taking the case of Mekdem Ethiopia National Association, Mekdem in focus.

The Government of Ethiopia under the Ministry of Heath has launched the Health Care and Support Program (HCSP) with two consecutive Road Maps in 2010. The first Road Map is aimed at enhancing the activities on expanding antiretroviral therapy (ART) services, and the goal of which is achieving universal access to comprehensive HIV & AIDS services by 2010. Though CHBC is provided in the home, it is part of an integrated approach in the care, support and treatment of HIV/AIDS. CHBC involves a variety of services, provided primarily by an organization (NGO/FBO/CBO) which is linked to various facilities/groups. The whole site approach is complemented by an emphasis on community- and home-based care and on linkages through health posts, kebele-oriented outreach workers (KOOWs), case managers, nongovernmental organization (NGO) outreach workers, mothers' support groups, and other available mechanisms on the ground (USAID,2008).

In line with the global action the Federal Government of Ethiopia has developed important policy and strategic instruments. National Task Force was established in 1985, National AIDS/STD Control Program (NACP) in 1987 (WCC, 2003); two medium term prevention and mitigation program were implemented between 1987 and 1996 (GFDRE, 2000), produced and implemented guidelines on sentinel surveillance and counseling and also launched a national policy on HIV/AIDS in 1998 (Fekadu&Jemal, 2005). A National AIDS Council was established in 2000. Following this HIV/AIDS Prevention and Control Office (HAPCO) was established. Several relevant policies and regulations further formulated including HIV testing policies for diagnostic and clinical purposes, including professional codes to ensure confidentiality, disclosure policies of HIV testing and resulting provision and comprehensive programs. According to World Health Organization all the aforementioned actions need a collaborative effort of the private and the public sector, NGO/CBOs, the government and individuals and groups.

According CSO Taskforce User's Manual on Charities and Societies (2011) Charities and Societies Agency has registered about 1600 CSOs and out of which more than 1500 are Ethiopian resident and foreign charities working on development and welfare. Therefore Mekidim Ethiopia National Association is among the 1500 NGOs exclusively working in HIV/AIDS intervention that operate on a limited scale, reaching only a small fraction of the population (MENA Brochure 2005). It was established in 1997 by people living with HIV/AIDS and AIDS orphans. MENA is organized to fight against HIV/AIDS, to addresses stigmatization of people living with HIV/AIDS, the lack of care and support, the lack of involvement in prevention programs and other issues affecting people living with HIV/AIDS. People living with HIV/AIDS in Ethiopia often face ostracism, stigma, rejection and isolation by community members, family, and their associates.

Therefore, MENA works to address the human rights of people living with HIV/AIDS and provides ongoing holistic care and support for its members, persons infected with and affected by HIV/AIDS. In its advocacy program, the association is pursuing with the government the provision adequate provision of care and support to people living with HIV/AIDS and orphans. Currently the Association has opened five branches in Dessie, Jimma, Bahir Dar, Nazareth and Shashemene. The number of members, which was 12 in 1997, now reaches more than 5000 including family members.

1.2 Statement of the Problem

This study mainly intended to review and evaluate the home based care and support available to Persons living with HIV/AIDS (PLWHA) and family members of Mekidim Ethiopia National Association (MENA). A holistic and comprehensive care and support program has been developed and best practices introduced for a better adoption and implementation to address the wide ranging needs of HIV infected and affected persons parallel with minimizing the negative national and individual effects of the pandemic and installing the hope of PLWHAs to continue functioning.

No matter what efforts are on the ground, HIV/AIDS is spreading fast; adding new infections to the already existing insufficiently cared for and supported nations. Though

funding has increased, because of inefficient utilization and denial of many national leaders about the impact of AIDS on their people and societies, many needy persons do not get access to the basic supports (UNAIDS, 2004). Approximately 90% of people living with HIV or AIDS have extremely limited access to quality care and to new treatment (UNAIDS, 2000).

Therefore, it is critical to determine the most effective means of treating and care for people living with HIV. In sub-Saharan Africa, an estimated 4.3 million people need AIDS care but only about 12% receive it (WHO, 2004). Globally, there are also enormous disparities in spending. Per person living with HIV in the United States exceeds 1000 times in Africa (UNAIDS, 2004). In Ethiopia, HIV/AIDS, being an expensive disease that requires a considerable amount of resources from the health system, is estimated costing from 425 to 3140 Birr (average of 1800 Birr) during the course of the illness for hospital care for an AIDS patient (WCC, 2000).

As MENA is working in resource constrained settings, members of the association, people living with HIV/AIDS and AIDS orphans, might not be able to get the required care and support services. Evaluating this program helps to pinpoint best practices and to gear interventions towards a best result.

1.3 Objectives of the Study

General Objectives

The main objective of the study intends to assess the practice of the Home-Based Care and Support Program of MENA to its affected clients. The study also addressed:

Specific Objectives

- To identifying the types of services(care and support) being delivered to the clients;
- To assessing the practice and the nature of the HBCS Program in relation to the set rules and standards;
- To investigate the achievements and challenges of the HBCS Program;
- To investigate strengths and constraints of Association and the HBCS condition ;
- To indentify the best practices by the HBCS providers in the HBCS process

1.4 Study Design and Methods

The methodology is designed to include measurable facts, developments from client's caregivers, and experts of MENA and HIV/AIDS Prevention and Control Offices (HAPCO). Experts and officers implementing the program in MENA and HAPCO and beneficiaries/ clients/ of the association were an integral part of this study. In the review and evaluation of the home based care and support program of MENA, the guide and indicators developed by World Health Organization of the year 2000 is used.

1.5 Universe of the study

Mekidim Ethiopia National Association has branches in Dessie, Jimma, Bahir Dar, Nazareth and Shashemene towns. The study covers the home based care and support program of Addis Ababa branch of Arada and Gulele sub cites.

1.6 Sampling methods

The study will employ a Simple Random Sampling that allows making a quantitative analysis from limited study population. Therefore from a total of beneficiaries 1,000 households, 75 parents (50% are mothers) will be considered. Secondly, the study will use Purposive Sampling technique include professionals and experts involved in the in the program. 7 caregivers will be included in addition to the project manager from Mekdem

1.7 Data Collection Tools and Procedures

Sources of the Data

Primary and secondary sources will be consulted to obtain information about the topic under study. Primary data will be gathered through questionnaires in relation to objectives' and research questions of the study. In addition, reports, fact sheets and project documents were consulted. Official reports related to the topic in the study will be solicited from the Addis Ababa University, HAPCO, MoH and electronic publications from international organizations such as WHO, UNAIDS, individual country reports on

care and support etc will also be used for the same cause. The study will also use books, journals, newsletters, project documents etc as a secondary data sources.

Data Gathering Instruments

The research instruments employed for data collection will be three separate sets of questionnaires (for clients, caregivers and MENA experts. Moreover, questionnaire enables to obtain variety of opinions from a large size of population. Therefore, it is believed that questionnaires help further strength the information collected by means of other data gathering instruments.

1.8 Data Processing and Analysis

To make the collected data ready for analysis, the questionnaires will be checked for completeness, the data will be classified and tallied carefully, the assembled data will be arranged and organized in tables, and computed using percentages. Finally, the organized data will undergo the interpretation process for the study analysis. The statistical measurements such as frequency, percentage, and mean score will be used for analysis.

1.9 .Organization of the Study

The study is organized in five chapters. The first chapter deals with the introduction of the study. The Second chapter is dedicated to the review of the related literature. The third chapter describes the study design and methodologies used. The presentation and analysis of the data collected and interpretation of the findings are included in chapter four. The fifth chapter presents summary, conclusion and suggestion for action**.**

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