Review and Evaluation of the Care and Support Programs of Mekidim Ethiopia National Association for Persons Living with HIV/AIDS and their Family

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SCHOOL OF SOCIAL WORK

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Abstract

The situation of HIV/AIDS is very frightening in Ethiopia. It has brought multifaceted problems to the nation. As AIDS is more pronounced in the adult age group, their death left many children without parents. The civil society, governments and non governmental organizations has been implementing expanded and comprehensive intervention to won the pandemic. Mekidim Ethiopia National Association is one of these organizations. MENA is working in resource constrained settings and it was assumed clients might not be able to get the required services. This review and evaluation study which intended to give the current picture of the services and assess the differences made in the lives of clients, serves the purpose of informing and guiding HIV/AIDS program designers, policy makers, program implementers and researchers in improving interventions. The study used qualitative methods. The study found that the financial constraint in the association hindered to address the socioeconomic needs of clients. However, the other services helped most to live positively with the virus and to see their future with hope. To improve the quality of services MENA, is required to assure beneficiaries participate in the program, increase its financial status and to make timely monitoring and evaluation.

Key words: care, support, monitoring, evaluation, services, participation, infected, affected, HIV/AIDS, beneficiaries, association.

CHAPTER ONE

1. BACKGROUND OF THE PROBLEM

Human beings have been suffering from manmade and natural disasters for long periods, however HIV/AIDS is said to be the worst of all infectious diseases to confront the world since the bubonic plague of the year 1347 (Family Health International [FHI], 2001). The global HIV/AIDS pandemic is the worst infectious disease, a terrifying and catastrophic problem of our time (UNAIDS, 2002). It is acknowledged to be the gravest health, social and economic development challenge to prospects and global security of the world at the moment (World Counsel of Churches [WCC], 2003). AIDS, after its first identification in 1981among homosexual men and intravenous drug users in New York and California, grew and spread like a wild fire among heterosexual men, women, and children affecting and virtually claiming the life of many people worldwide (Microsoft Encarta, 2003).

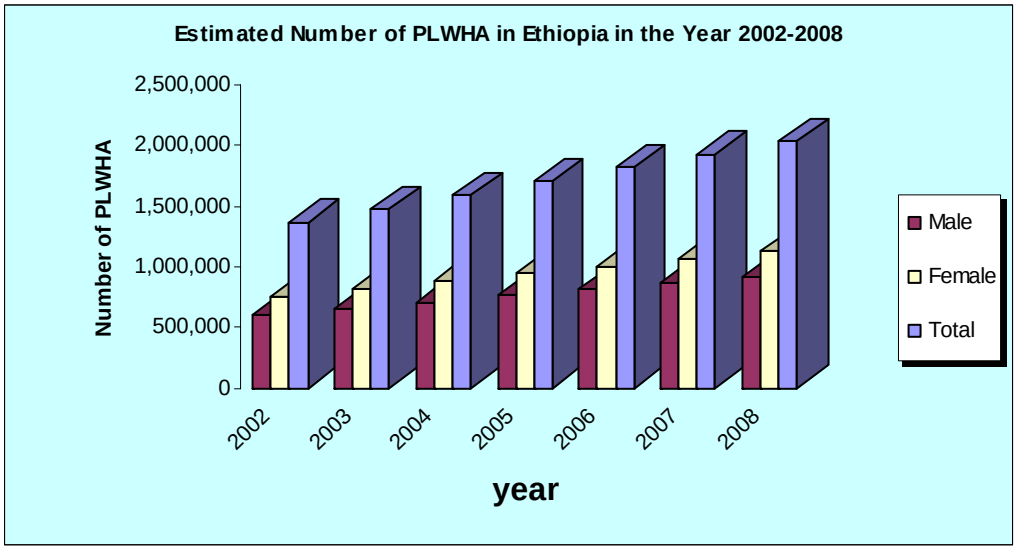
Right after the identification of AIDS there has been a global attempt to record the number of people infected and affected by HIV/AIDS, however the true number of HIV/AIDS cases and figure is not possible to find for many reasons (UNAIDS, 2004). Dislike by some people to seek hospital care for HIV/AIDS; death of some people with HIV infection of other diseases before they are diagnosed as having AIDS; lack of capacity by many rural health care facilities to test HIV infections and lack of access by many people for health services; and the poor practices of recording and reporting culture are among the causes for the poor information on HIV/AIDS statistics (WCC, 2003). However, due to the development of more comprehensive country surveillance and improved methods, as time goes on, more accurate data are being generated (UNAIDS, 2004).

According to UNAIDS (2005) since its eruption AIDS has claimed the lives of more than 25 million people and currently it is estimated 36.7 – 45.3 million people living with HIV in the world. Despite efforts aimed at controlling it, AIDS continues to spread in an exponential manner particularly in Sub-Saharan Africa.

Poverty, social and political injustice favors AIDS to spread rapidly (Eyerusalem, 2001) and hence it began earlier and has progressed further in Africa (Save the Children UK, 2001). More than 95% of the HIV victims live in developing countries (WHO, 2000) out of this 70% (25million)are living Sub-Saharan Africa (UNAIDS, 2004). AIDS is frightening in this continent.

Ethiopia is one of the Subs –Saharan African countries characterized by absolute poverty with GDP per capita $115 political, economic, social welfare, education and health challenges (Save the Children Alliance, 2001) and recurrent drought. Besides these problems, Ethiopia is also known for frightening prevalence and alarming spread of HIV/AIDS. HIV/AIDS, 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 [MOH], 2004 fact sheet). The impact of HIV/AIDS in Ethiopia has been devastating. The following table shows how HIV/AIDS is progressing and alarms the need for meaningful interventions.

Table 1. Estimated Number of Persons Living with HIV/AIDS in Ethiopia in the year 2002-2008



Source: adapted from Federal Ministry of Health, (2004). *AIDS in Ethiopia (5th ed.)*.

The table reveals HIV/AIDS is progressing from year to year. Data obtained from the same source indicates the number of PLWHA in the capital city is increasing alarmingly.

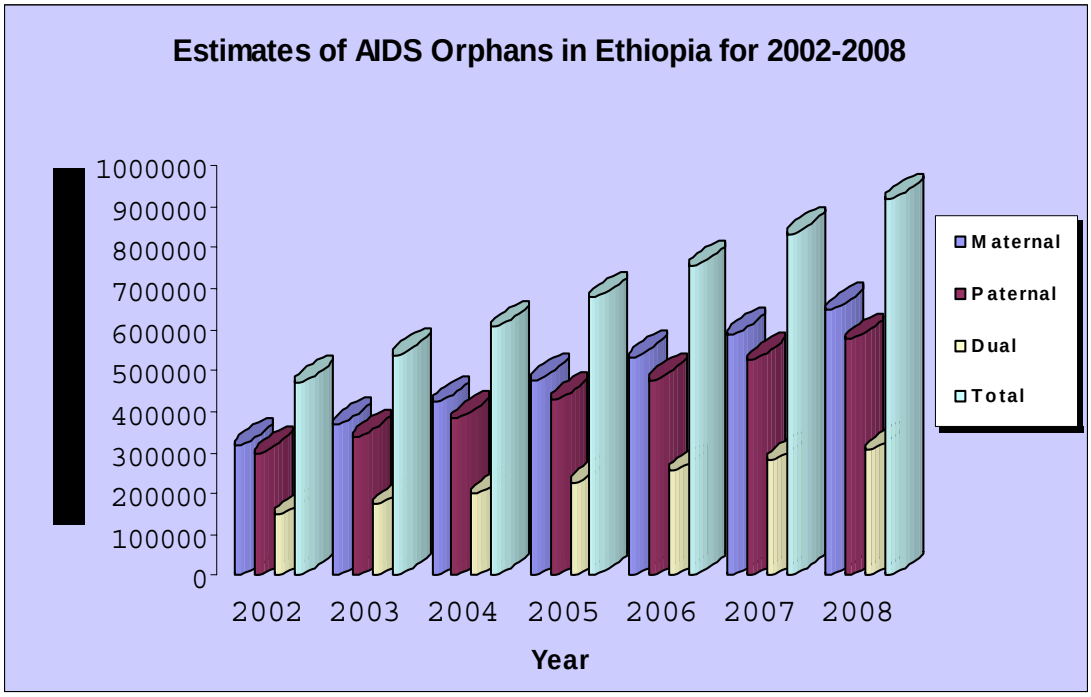
HIV/AIDS is more pronounced in adult age groups (15-49). According to World Counsel of Churches (2003) and MOH (1998), 91% of reported AIDS cases in Ethiopia are in this age group. As this age group of persons are the economically active, the social and economic basis of the family and the society their 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[1] 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).

[1] UNAIDS defines an orphan as a child under 15 years of age who has lost her or his mother (maternal orphan) or both parents (double orphan) to AIDS

Ninety five per cent of children orphaned by the pandemic live in this continent (Save the Children UK [SC UK], 2001).

The Ethiopian MOH estimated the number of children under age 15 that lose at least one parent or both due to AIDS as shown in table 2.

Table 2. Estimated Number of AIDS Orphans in Ethiopia in the year 2002-2008



Source: adapted from Federal Ministry of Health, (2004). *AIDS in Ethiopia (5th ed.)*.

The actual number of AIDS orphans is slightly less than the previous estimate however the number is increasing. The MOH statistics also shows that currently there are over 79, 000 AIDS orphans in Addis. This number is expecting to rise due to rural urban migration and other related factors.

1.1. INTERVENTIONS IN ADDRESSING THE PROBLEM

Recognizing the magnitude of this problem, leaders from civil society, governments and multinational agencies declare HIV/AIDS the single most critical security and development

issue and require implementing expanded and comprehensive intervention (WHO, 2000). In this comprehensive programs, care and support is one of the vital components which has multifaceted benefit in mitigating the effects of the pandemic on individuals, families, communities, and nations. Such interventions are an important component of the overall response to HIV/AIDS because they increase the impact of prevention strategies and mitigate the negative consequences of the epidemic on the prospects for sustainable development.

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.

1.2. MEKIDIM ETHIOPIA NATIONAL ASSOCIATION

Mekidim Ethiopia National Association is among the 92 NGOs exclusively working in HIV/AIDS intervention that operate on a limited scale, reaching only a small fraction of the population (GFDRE, 2000). 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.

1.3. STATEMENT OF THE PROBLEM

This study mainly intended to review and evaluate the 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. 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. Therefore, reviewing and evaluating the association's program is vital in improving the intervention and developing relevant and adequate responses. The paper also attempts to contribute to the literature pertaining the best practices in addressing the care and support needs of HIV infected and affected persons.

1.4. OBJECTIVES OF THE STUDY

The main objective of the study is to review and evaluate the care and support program of MENA in making a difference on the lives of persons living with and families affected by HIV/AIDS. Besides, it has the following specific objectives:

- Assess and analyze the existing services :-
    - to what extent are planned intervention activities actually realized?
    - what services are provided?
    - to whom and when? and
    - for how long,
- Assess the progress of the program in achieving program goals and objectives
- Assess beneficiary selection and referral system
- Obtain an understanding of how monitoring and evaluation plans developed and executed by the organization.

1.5. THE PURPOSE OF THE STUDY

Reviewing and evaluating HIV/AIDS care and support program of MENA, an indigenous nongovernmental organization, which serves the following purposes:

- To serve MENA, by identifying strengths, in looking its efficiency and effectiveness in implementing program activities meeting goals and objectives of the association as well as improving and scaling up the design and implementation of holistic and comprehensive interventions.
- To present, to some degree, the current picture of care and supports available for HIV/AIDS infected and affected persons in the country against the globally agreed recommendations and best practices thereby informing and guiding HIV/AIDS

program designers, policy makers, program implementers and other concerned bodies and researchers for better interventions.

- To serve as a springboard for future professional social work students and others to carry further professional research.
- To suggest practical advice on the significance and role of professionally trained social workers in HIV/AIDS interventions based on the study findings.
- To identify the best practices of MENA.

1.6. RESEARCH PROCESS

The research is conducted on the care and support program of Mekidim National Association Addis Ababa program. The whole research process (proposal formulation, data collection, analysis and report writing) goes from January-June 2006. Primary and secondary data were collected during March 2006.The researcher in collaboration with his colleague collected the primary data. No special software utilized for primary data processing. The Addis Ababa University has granted Br. 2085.00 (two thousand eighty five) for conducting this research and the School of Social Work assigned a research advisor.

1.7. RESEARCH RELEVANCE AND CONTRIBUTION TO SOCIAL WORK

The review and evaluation of the care and support program of MENA has significant relevance to social work practice. This relevance is described in relation to the mission of social work.

The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty (National

Association of Social Workers [NASW], 1999). In this regard, the review and evaluation result will inform the primary needs of the vulnerable groups, PLWHA and AIDS orphans, and the best ways to address these needs with the objective of empowering MENA in its effort to provide quality services.

Social workers promote social justice and social change with and on behalf of clients. As PLWHAs and AIDS orphans suffer from stigma and discrimination and lack the provision of proper attention in their medical, socioeconomic, psychological and legal supports the findings of the study help to effect advocacy services on behalf of these groups of people for a better interventions and considerations.

The study will have also the relevance with social work practice by presenting the gaps that need direct social work practice, community participation, the actions of the state and persons in power, policy development and reinforcement, and the areas which needs further research and evaluations. In general, the study being sensitive to the impact of HIV/AIDS on individuals, family and the society strives to promote social justice through the advocacy of rendering comprehensive care and support provision for the HIV/AIDS infected and affected persons which improve the quality of life.

1.8. RESEARCH COVERAGE

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

CHAPTER TWO

2. REVIEW OF LITERATURES

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.

2.1. RATIONALE FOR CARE AND SUPPORT SERVICE PROVISION

According to the World Health Organization (2000), the rational 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).

2.2. PRINCIPLES AND VALUES OF CARE AND SUPPORT SERVICES

The provisions of any services needs to systematically and well designed and based upon widely accepted principles and values. The World Health Organization understanding 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.

2.3. OBJECTIVES OF HIV/AIDS CARE AND SUPPORT PROGRAMS

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

- 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, and
- To improve the survival of PLWHA

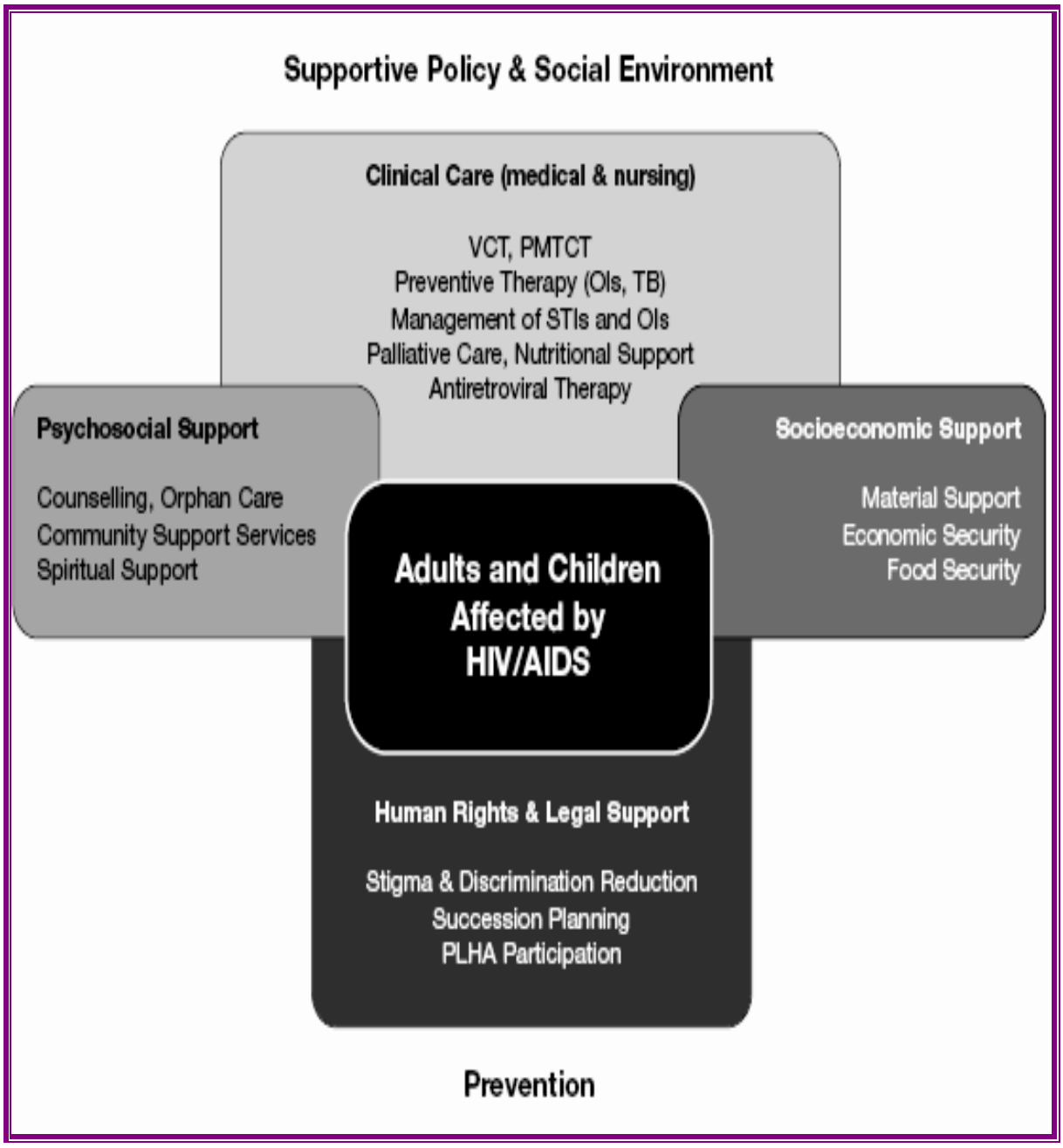
Specific objectives:

- To strengthen and promoting 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

2.4. COMPREHENSIVE HIV/ AIDS CARE AND SUPPORT PROGRAM

The needs of PLWHA are wide ranging. As HIV infection and illness steps forward, the types of services required also changes (FHI, 2003a). Therefore, a complete and a broad range services that include supportive and complementary services are required to address these wide ranging needs of PLWHA 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 following figure.

Figure 1 The Four Main Domains of HIV/AIDS Care and Support Services



Source: Family Health International, Treatment Division, in 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[2], 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).

- **Psychological needs**

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).

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[2] 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).

- **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

any settings in health facilities, in communities and in the workplace promoting equal access 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, to the aforementioned dominant care and support service components, care for the caregivers is supplemented to provide comprehensive services.

- **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 PLWHA. 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).

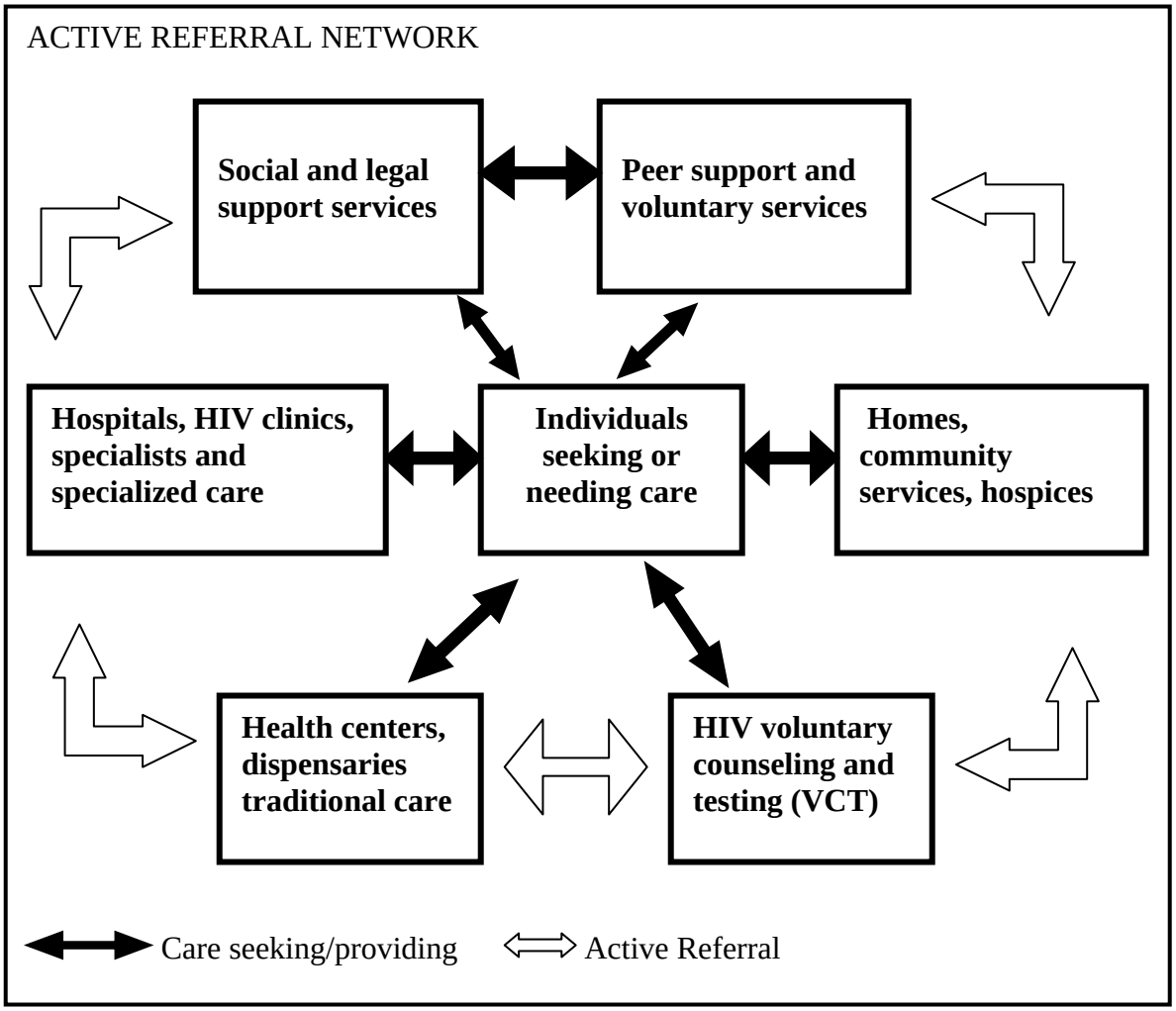
2.5. CONTINUUM OF CARE AND SUPPORT

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. There 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) .

Figure 2. Comprehensive HIV/AIDS Care and Support



Source: Adapted from Family Health International Treatment Division in WHO, 2004 .p 9.

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. In the figure it is shown 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).

2.6. 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 3. Care and Support Activities According to Need, Complexity and Cost

Care and Support activities, according to need, complexity and cost	
Essential activities	• HIV voluntary counseling and testing • Psychosocial support for PLWHA and their families • Palliative care and treatment for common OIs : pneumonia, oral thrush, vaginal candidiasis 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)
Care and support activities of intermediate complexity and/or cost	**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

Care and support activities of high complexity and/or cost	**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 atypical mycobacterial 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.

2.7. 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

Design), Process Evaluation (Monitors Inputs and Outputs; Assesses Service Quality), 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.

CHAPTER THREE

3. METHODOLOGY

3.1. REVIEW AND EVALUATION METHODOLOGY

In reviewing and evaluating the care and support programs of MENA the study basically used qualitative methods in the forms of focus group discussion (FGD), 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 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 care and support program of MENA, the guide and indicators developed by World Health Organization of the year 2000 is used.

3.2. DATA SOURCES

This evaluation is purely a process evaluation. Data for this process evaluation were collected from primary and secondary sources using qualitative techniques. Particularly, data was collected from sixteen focus group discussants (beneficiaries of the association), from two beneficiaries' representatives of sub cities, one officer of the association and one from an official of the Addis Ababa HIV/AIDS Prevention and Control Office(HAPCO). In general, regarding their knowledge and experience, twenty subjects are within the range of the required data. Observation was also made to substantiate data collected from these respondents. In addition, reports, fact sheets and project documents were consulted.

3.3. DATA COLLECTION METHODS

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. Homes of five home care beneficiaries (three PLWHAs and two orphans) visited to assess their situation with regard to household condition and integrations in the neighborhood. 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.

Focus Group Discussion -Two FGDs with eight PLWHAs of each sex were conducted to assess and analyze the existing services, beneficiaries' participation, and improvement in the living condition of the target groups.

Interview- Semi-structured interview with two representatives of the beneficiaries, staff/expert working in the association and expert from HAPCO were conducted on practically existing care and support services, results obtained and government's interventions respectively.

3.4. DATA COLLECTION INSTRUMENTS

In order to collect qualitative data, two instruments were developed and used. Focus Group Discussion Guide consisting of 10 major questions that help the researcher in facilitating the discussion with sixteen focus group discussants, three interview guides consisting of 6,7 and 10 items were developed and used with the HAPCO official, MENA official and beneficiaries' representatives respectively.

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) where he was assigned for his field placement. Accordingly, some relevant and minor changes were made and the final versions of the data collection tools were developed.

3.5. DATA COLLECTION PROCEDURE

As part of the understanding of the objective of the review and evaluation 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. With this in mind, the researcher applied the following procedure.

The principle underlying FGD indicates that FGD should be conducted to each sex category with age proximity for open, free and unreserved participation. In this study, different discussion session was organized for each gender and participants were selected according to

age proximity. The age range for the male and female group was from 27 to 38 and 23 to 27 respectively. All these participants are living with the virus knowing their serostatus from the least 2 to the highest 15 years. Physically all seem well but two men and three women were observed having some cough. The women's group dressed in clean clothing and appears more presentable than the men's group. Their physical appearance and dressing leads one to conclude they are from the poor segment of the population. Externally they showed no depression and all were very much interactive.

The FGD was conducted in the premises of MENA on an off day-Saturday, and to avoid interruption and give an opportunity for the discussants to have free talk and to protect them from any forms of biases or fear. The average time taken for the discussion was one hour. The FGDs were run by the researcher as facilitator and notes were taken by his assistant. With the consent of the participants, discussions were recorded on audiotape for the purpose of this research only. The discussants came 15 minutes ahead of the schedule showing their cooperation. All were active participants in the discussion, even to the extent of revealing their personal cases which became relevant to the discussion. The women's group was found to be relatively more transparent in revealing facts.

The researcher interviewed beneficiaries and their representatives and officials from HAPCO and MENA. Oral consent from beneficiaries participants and written consent from MENA and HAPCO officials obtained ahead of interview and discussion dates. All the interviews and FGDs went smoothly with no problems. Both offices, MENA and HAPCO, provided access to use the office computers for data processing.

3.6. DATA 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. The evaluation information to be of help to any organizations working on HIV/AIDS 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 FGD, observation and interview analyzed 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 care and support program of the association.

3.7. IMPORTANT PRINCIPLES EMPLOYED IN THE RESEARCH

To collect reliable information the review and evaluation of the 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

3.8. ETHICAL ISSUES

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.

3.9. STRENGTH AND LIMITATIONS OF THE STUDY

STRENGTH

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

LIMITATIONS

The limitations of this study were 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 care and support program of MENA.

CHAPTER FOUR

4. PRESENTATION OF THE FINDINGS AND ANALYSIS

As mentioned earlier, this review and evaluation research is purely that of a qualitative form. Data were collected using observation, interview, FGD and secondary data review. All the data were collected and organized in relation to the objectives set to review and evaluate the care and support programs of MENA. Here, an attempt has been made to present the relevant information as a summative form without analyzing the responses against each data collection process and focusing on the specific objectives set. This approach is preferred by the researcher, systematically to organize the data and focus on the content analysis as there is no attempt made to use any special computer software for data analysis.

4.1. GOALS AND OBJECTIVES OF MENA'S CARE AND SUPPORT SERVICES

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. 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 and focus group discussion held.

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, 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. Focus group

discussants mentioned that though the organization has a legal section in its structure, the expert has recently resigned from the office and thus they are not getting this vital support.

In order to assess to what extent the Care and Support Program addresses the felt needs of the client, focus group discussants were asked to identify the felt needs of PLWHA 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, FGD 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 PLWHA 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 Kebele 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.

During the focus group discussion in connection to the violation of rights and stigma and discriminations some of the women were overflowing with tears and anger presented what happened to them as follows:

Case 1

I was a five month pregnant and with the rule of prenatal care I had blood test for HIV/AIDS. The test result became positive. When I heard this result I was shocked and confused for a longer time. I know I had no blood contact from any source and have no sexual relation outside of my marriage. I am not liable for the case. After few days when I realize all the

things and became conscious as I am living with my husband's relatives in order to protect people around us during contacts at delivery, I have disclosed my serostatus to all these persons including my husband. He also checked his serostatus and found negative. It was unbelievable to me how couples have different test results. Right on that day thinking that I am the original source of the virus, parents of my husband forcefully separated us. I was forced to leave their home with out having my clothings and any other property but I refused. We started living in the same building but in different rooms. He took all properties with him leaving only night wears to me. He is still forcing me to leave his place. I have contacted Kebele and court but they are not dedicated to handle my case timely as I am a woman and vulnerable having no one to support me. The Kebele particularly is reluctant to protect my human rights. I am suffering from his beatings and frequent insults and from the neighbors' discrimination. No matter what exists now, I am trying to improve my situation with the help of God.

Case 2

One of our friends was living with her husband's parents compound building with their own home of three rooms. The couples had also built welding and metal workshop in the same compound. The husband was sick frequently and his mother suspecting HIV/AIDS took them to a health center. Without getting their consent and with underground relation, the mother facilitated blood test for HIV with out the knowledge of the couples. They were giving no counseling and even the test result told by the mother as an insult while they were having coffee ceremony with the neighbors. The woman was nine month pregnant. When she heard this bad news she encountered labor and even in that moment she was told and forced to leave

the home as soon as possible and never to come back after delivery. Neighbor took them to hospital and a boy was delivered. As she was not allowed to come to the same home, some persons in that community helped her to get temporary shelter to live sharing one room with a beggar and his son in that village . Her husband died in 3 weeks time in connection with the stress and psychological problems he developed as his result was told inappropriately. The woman was denied any property by her husband's family. Kebele and other legal bodies started to do something to get her properties and some other legal supports but it has not progressed as they are not really determined and committed to handle such cases

Continuing listing the felt needs, the discussants further added the following:

- 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 PLWHA

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 PLWHA, incentives for those PLWHA 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 PLWHA and orphans, discussants were asked to point out the right beneficiaries to the different care and support programs of MENA. Before identifying the beneficiaries the discussants 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 PLWHA, community, Kebele 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 discussion of beneficiaries and their entitlement to the care and support provisions discussants uncovered that MENA gives priority for HBC and 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 conformed 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.

Discussants 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 mentioned 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 most needy groups for the care and support program of MENA.

4.3. CLINICAL SERVICES AND MANAGEMENT

In order to evaluate the standard and quality of medical services rendered for PLWHA, a MENA official was interviewed on the availability of trained staff to manage HIV-related illness, referrals for HIV infected patients and supervising palliative care. The interviewee disclosed that MENA has middle level nurses with progressive trainings that control and

manage overall health situations of clients. They are also assisted by two part time medical doctors. As to the referral, the officer reported, all medical cases beyond their capacity are referred to government hospitals via the established networks.

4.4. VCT SERVICES

During the discussion of services available in MENA, discussants revealed that there is no VCT service in the association. However, they disclosed that they get post test counseling and ongoing counseling. The interview made with the MENA official revealed that this counseling is given by one professional nurse counselor and two lower level counselors.

In order to see the importance of VCT and major principles in implementing the service, discussants were asked to give their views in relation to the counseling rendered there in. Most of them had a very bad memory about the pre and post test counseling they had during their blood test. They said, as time goes, counseling has improved. Most of the discussants remembered that they did not get appropriate counseling and most felt hopeless and even some express that they felt they were to die in a few days time. Some of the problems happened to them were the absence of confidentiality, emotional and psychological support, no link to care and support, no hope installation, no advice on nutritional intake, etc. However, when they get into MENA, they said they started to live with hope getting the best counseling for each of their cases. The officer elaborated this point as the various studies conducted indicated that the majority of counselees had expressed that they got proper counseling. One of the discussants, filled with tears, said if we had not had that counseling at that time from MENA we might not be able to see each other now. It is disclosed that there is appropriate posttest and ongoing counseling for individuals, couples, family and group as per the need of the client with proper attention and follow up of the principle of counseling both at the premise of the association

and at the client's place. The following box presents the client's word about how they feel about the service.

Case 3

I had blood test for HIV 15 years ago. I had no pretest counseling. In the so called posttest counseling, I was told I am infected with the "*Addisu beshita* " named HIV and I was told to have only five years to live. During that time I had over Br.100, 000.00 and a marriage. I lost everything- money, marriage, hope, love for others, appetite for food, courage for life, etc. I felt that when each tomorrow comes my days are decreasing thus pulling my day of death. I was sick everyday living alienated from others. I was living with full distress. With this trend the 5 years got completed but I started living extra days than I was told to live. After these days, with the advice of a friend I came to MENA to get some counseling support and to see how PLWHA are living. I got counseling and proper follow up and little by little started to live with hope. Few days later I developed the full meaning of life and started to engage in productive works and helping people who are in my previous position. Thanks God.

Case 4

For an unknown reason I was sick and went to hospital for treatment. Looking at my physical status, the doctor advised me to have blood test. Taking the pretest counseling I had the blood test. However, when I returned for the result the medical doctor even without allowing me to sit told me that I am living with the virus. I was shocked, even tempted to quarrel with him for his misbehavior. For certain periods, I lived alienated with persons. One afternoon, since I came to know MENA's program via mass media, I

went to MENA and disclosed everything happened to me and obtained counseling for continuous periods and started to live integrating with others and with strong sense of living positively with the virus.

With the strong desire of knowing what contributes for the strengths of the counseling of MENA, FGD and interview participants initiated to reveal factors that contribute for the strengths. Accordingly the following are listed: the provision of counseling program for each group of individuals, couples family and group as per their need, the existence of PLWHA in the association to be exemplary for continuity of life, the devotion and commitment of staff, the existence of other supports, the use of PLWHA as a counselor, the existence of peer support group, the experience of the association and the willingness of staff to support others were mentioned.

4.5. ADDRESSED NEEDS OF PLWHA AND ORPHANS

To assess the contribution of the care and support services in addressing the felt needs of the clients, discussions were held with FGD participants. They started reviewing their situation before and after they got access to MENA services. Most of them eloquently uncovered that before coming to the association they were living doubting their future, having complicated psychological problems, physically weak, alienating themselves from the society, losing meaning to life with no value between life and death, etc. All in all, they had no hope of living positively with the virus and assumed that they would die in the very near future. However, they stated that the mere opportunity to see other persons living with the virus for longer years being the member of the association significantly changed their life to continue with hope and to live positively with the virus.

All of the following project activities were described by FGD participants and beneficiaries' representatives as addressing the needs of clients and made a real difference in their lives: the counseling service, support of PLWHA groups, HBC, skill training, income generation scheme, housing rent coverage, ART provision, medical and diagnosis cost coverage, transportation fee supports, school related expenses coverage, training on counseling, all supports given for bedridden patients, the weak and TB patients.

Interview and discussion held on frequently reported complaints. These findings are presented in the following table..

Table 4. Most frequently reported complaints

Major problems	Respondents	
	FGD participants	Beneficiaries' representatives
Socioeconomic support for those not bedridden	X	X
All around orphan support	X	X
Nutritious food support for ART users	X	X
Support on stigma and discrimination	X	
Job for skill trained persons	X	X
Monthly food distribution for orphans	X	
Absence of strong network with kebeles	X	
Legal support on inheritance rights	X	
Blanket and bed sheet support	X	
Screening procedure on identifying the most needy beneficiaries	X	X
House rent coverage	X	X

The table shows most of the frequently reported complaints are from socio economic and need of legal supports. Both FGD participants and beneficiaries' representatives felt the problems. According to the responses of FGD participants and beneficiaries' representatives, the major causes were: lack of fund, absence of beneficiary consultation and participation and absence of timely monitoring and evaluation of activates. The interview conducted with MENA officials confirmed that insufficiency of resources and supplies are the root sources of the problems to render the optimum care and support needs of beneficiaries. According to him, this happens because of the larger number of needy clients.

4.6. BEST WAYS IN ADDRESSING NEEDS OF PLWHA AND ORPHANS

Parallel to identifying needs of PLWHA and orphans and the supports given to them, focus group discussants were given the opportunity to discuss the modalities of effective and efficient service provision in relation to the beneficiaries' needs and the prevailing capacity of MENA. In pointing out the better way of service deliver discussants expressed their views in relation to the problems or constraints observed in providing optimum care and support services and in relation to the most frequently reported complaints.

- **Advocacy and strong networking**

Advocacy and strong networking with government administrative bodies particularly with city, sub city and Kebele administration was raised repeatedly with greater concern as one of the best ways of service delivery.

- **Enriching economic potential**

In ordered to address the wide ranging needs of clients, addressing the ever increasing number of members of the association and enriching the economic potential of MENA, participants unanimously agreed and suggested to devise effective means of involving donors,

the public, government and all concerned bodies in all phases of the program. During the discussion to emphasis on special effort for securing fund one of the older member of the association said “during the first few years of MENA’s establishment, the number of members was 900 and now has reached over 5000 which means, unless donors properly understand this increase and cooperate, MENA can not satisfy all the needs of all beneficiaries except membership opportunity’’

- **Strengthening relations with schools**

With reference to networking issue, participants also emphasized the need to strengthen MENA’s relation with schools where AIDS orphans learn. Children from HIV infected and affected families face greater stigma and discrimination at their earlier age from their peers in the school. Establishing or strengthening relation with school and community helps to raise awareness of the pupil, to get the support of teachers for follow up and for addressing stigma and discrimination issues.

- **Beneficiaries participation**

The FGD participants also raised the need for meaningful participation of beneficiaries in all levels of the project cycle. As to the importance of their participation they mentioned that participation ensures project ownership, helps to identify and access the rights of beneficiaries to the right services, assures transparency of program implementation and in prioritizing the needs of each beneficiary and the implementation of activities.

- **Expanding thoughts beyond HBC**

Escaping out of the notion of giving special attention and priority for the weak and bedridden patients is also mentioned as one of the best ways of providing quality services. Discussants with bitter emotion expressed that in the association, to get relatively better

services, you need to be either physically weak or bedridden patient. In this case they added if timely assistance is not given to the needy, gradually they turned to be weak and chronically ill. Thus supporting at this later stage would not deter the person from dying. Therefore, they suggested giving proper attention and support to all the needy before their case get worsened.

- **Limiting the number of clients**

Limiting the number of members of the association is also mentioned as one of the best strategies which further help the decrease in the burden of workload of staff, matching the available fund and program with the needs of the beneficiaries to make tangible difference on the clients.

FGD participants also mentioned that the establishment of full VCT service in the association will help in providing better services via accessing the client with the existing care and support services and to help people get a well experienced counseling service from the association.

- **Establishment of VCT services**

Discussants also revealed that since there are no VCT services in MENA, all came via their initiation without having proper referrals and they get assistance late than their situation urges. They expressed that they were looking for such support and shopping from here and there with the absence of proper knowledge of the exact place for care and support. Bearing in mind the problem they face to get early assistance and the change they had from MENA, they suggested the establishment of VCT services there.

The interview conducted with beneficiaries' representatives concludes the responses obtained from FGD participants by mentioning the support to beneficiaries prior to getting weak and becoming bedridden, other ART choices, limiting the number of beneficiaries

according to the budget, limiting the scope of services, seeking reliable fund source, awareness creation to the public on the programs of MENA, strengthening the medical service along with establishing VCT service, and coordinating and integrating works in providing comprehensive supports.

4.7. GUIDELINES, POLICIES AND STRATEGIES

Among the various requirement to effect quality care and support for PLWHA and AIDS orphans there is a need for policies, and guidelines. This also needs to be adapted with the local condition. The interview with HAPCO expert pointed that Ethiopia has adapted these policies, guidelines and protocols to its local conditions. These include HIV/AIDS Policy, (August, 1998), HIV/AIDS Strategies Planning and Management (2004-2008), Monitoring and Evaluation Framework (2003), National Mainstreaming Handbooks, Workplace Policy and Care and Support Guideline. As to the use, MENA officer interview shows it applies these important documents adapting to the local situation with the objective of HAPCO. In order to assure proper applicability of these, HAPCO official stated that HAPCO provides funds, capacity building training resources and technical assistance for monitoring and evaluation and established strong network for follow up.

4.8. BENEFICIARIES PARTICIPATION

One of the elements of providing qualitative service for PLWHA and orphans is their participation in all the project phases. Focus group participants and beneficiaries' representatives were asked to show the extent of their participation in the program and how they need to be involved. During the discussion it is clearly noticed that all participants don't have common understanding what participation means. Participating and attending meetings

was taken as participation. This was mainly observed in male FGD participants. The male group said they are participating in the association while the women group uncovered no participation at all except the quarter and annual program meetings. To make participants clear on participation they were given highlights on the meaning and ways of participation. After the explanation all the participants disclosed that there is no participation either individually or by their representatives at any level. The interview conducted with the MENA official confirmed that there is no participation of beneficiaries in assessing and accessing beneficiaries with the existing care and support services. Selection is undertaken by technical staff of the association. The interviewees strongly inquire MENA to participate beneficiaries in all appropriate stages of the project to help improve project activities.

4.9. INTERACTIONS AND INTEGRATIONS IN MENA

MENA works with volunteers and employed staff who live with or without the virus and serving clients infected/ affected by HIV/AIDS. Positive attitudes and harmonious interactions of these persons positively contribute to the smooth implementations of programs and in rendering quality services. Therefore, beneficiaries and representatives who are living with the virus and working in the association were interviewed on their reflection about the interaction and integration in MENA. Interviewees quickly responded that serostatus has no impact on staff and staff-client relationships. The work atmosphere is said to be serene and pure from any discomforts and is encouraging to work harmoniously. They further added , MENA is the best exemplary place to learn a community free of discrimination and stigma and a close relation and interaction of all persons. The researcher has observed this smooth and encouraging staff and beneficiaries relation and interactions. This is the best asset to attain goals and objectives of the organization assuring project ownership.

4.10. BENEFICIARY SELECTION AND REFERRALS

The needs of PLWHA vary with the stages of the disease. In order to know how beneficiaries' needs are assessed in the association and how they accessed with the care and support services, FGD participants were requested to discuss their thoughts. All the participants discussed that MENA has set criteria for each component of the care and support services. Those who fit with the stated criteria will be given the assistance. This process works particularly for the socio-economic support. For the other services, there are no special criteria. In most of the instances, priority is for the bedridden, physically weak and for those infected by opportunistic diseases and TB.

With the intention of knowing what strategy is implemented to access beneficiaries with their needs, an interview was conducted with MENA officials. The official expressed that as the needs of HIV/AIDS infected persons varies with their health condition, there is a strong communication network and referral system within the association to decide the type of support appropriate for each beneficiary but funding shortages limit provision of the required services.

In assessing the accessibility of services to any of the needy PLWHA and orphans, of beneficiaries' representatives were asked if the association underserve or refuses any group of persons. The interview revealed that as the mission of the organization is to provide qualitative care and support services to all the needy, MENA accepts all applicants to its membership with out any discrimination and marginalization.

4.11. ATTITUDE OF PLWHA TOWARDS THE CARE AND SUPPORT PROGRAM OF MENA

In line with the objective of knowing the differences observed by all care and support interventions of MENA and in assessing to what extent the goals and objectives of the association is realized, FGD participants were asked about their over all view and attitude towards the care and support services. Interviews were also made with this point with beneficiaries' representatives.

All the participants have a very positive attitude towards MENA. All the FGD participants agree that it has changed their life positively even to the extent of seeing their future with hope. Some of the sayings to express the contribution of MENA are as follows

" Mekidim is my father and mother which reads my inner feelings "

" Mekidim is my best place where I have persons to share my burden"

" Mekidim is my hope to take all the responsibilities to raise my child when I die"

" Mekidim is my source of happiness''

" Mekidim is the place which gave me true brothers and sisters whom you relay on at all good and bad days''

" Mekidim is the place where you do not come across any forms of stigma and discrimination"

" Mekidim is the place where we see and hear PLWHA laugh"

" Mekidim is the place where PLWHA think of improving their future"

Continuing their discussion, participants revealed that though they point out some weaknesses of project implementation procedures, they said that MENA's intervention has installed hope in all infected persons to live positively with the virus and to initiate themselves

to be healthy, psychologically adjusted, economically self sufficient and to live as any person whose serostatus is negative.

With the over all strength of the Care and Support Programs, FGD participants and interviewees identified the major strength of the association as:

- **Organizational** -The establishment of the association by persons infected and affected by HIV/AIDS and their commitment to serve these highly vulnerable groups, acceptance of all PLWHA and AIDS orphans in membership, establishment of different PLWHA support groups and creation of strong bond to install mutual and harmonies functional interactions, and the existence and applications of policies, strategic plans, guidelines, protocols.

- **Services**-Provision of posttest counseling by professionals and PLWHA both individually and on group basis, the provision of ART and medical services and supports of PLWHA support group.

- **Work atmosphere**-The existence of welcoming atmosphere in the association, the patience and commitment of staff to support others, facilitation of different opportunities for PLWHA and orphans to get love and affection and the close and integrative works of both PLWHA and other staff of the organization.

Staff of MENA is the direct implementers of the care and support services and they are in a better position to have track records of interventions and observed changes. Therefore, taking this fact the researcher held an interview with the expert, besides the interview with beneficiaries' representatives. Both groups were very much delighted in responding to this question. Among the changes observed they have mentioned the following:

- **Organizational**

PLWHA developed strong and widen web that enabled them to support each other.

- **Health**

Those who were bedridden get improved and becoming healthy, those who are getting ART has shown encouraging improvement, MENA helped many to reveal their serostatus which further helped to get early treatment and to prevent the spread of the virus, and death has decreased.

- **Psychological**

Belongingness felling developed, hope is installed to see their future with bright hope, PLWHA has developed strong feeling that their conditions improves, some PLWHA obtained training and seed money and started making their own money and became self-reliant which further developed the feeling of a contributing citizen, MENA helped to foster integration for those who alienated themselves, the existence of the care and support services helped as a pull factor for others to have blood test for HIV, and MENA helped develop a feeling of acceptance among PLWHAs.

- **Socioeconomic**

MENA helped orphans and PLWHA to resume their schooling and improve their conditions.

4.12. LESSONS TO BE LEARNED FROM MENA's CARE AND SUPPORT SERVICE INTERVENTIONS

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 representatives and FGD was held. These uncovered that the following services and methods of operation are the best practices that need to be adapted and continued.

- Provision of home based care services based on the felt needs of bed ridden PLWHAs through professionals and volunteer PLWHA.
- Provision of counseling both by professionals and PLWHA in individual, group, family and couple base by integrating live experiences of PLWHA and other pertinent groups.
- Establishment and closer support for PLWHA 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 (PLWHA) who are committed and having determined vision to improve the living situation of persons infected and affected by HIV/AIDS.
- Creating opportunities for PLWHA 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 PLWHA and those needing ART.
- Establishment of emergency fund allocations to cover costs related to medical services.

- Working together with locality idirs[3] to facilitate burials.
- Facilitation of appropriate opportunities and fertile grounds for staff, PLWHA trainees and families on inter and intra group basis experience sharing programs.
- The existence and reinforcement of team work among staff.

4.13. MONITORING AND EVALUATION

With the objective of assessing how monitoring and evaluation is planned and to what extent realized in the association, the following assessment was conducted. In line with the notion of process evaluation MENA official was interviewed how they plan and design monitoring and evaluation. Responding to this basic discussion point, the official uncovered that MENA designs monitoring and evaluation plan by its officers. He said, there is monthly and quarterly basis monitoring activities by its staff while evaluation is planned to be undertaken by external experts but it is not effected yet.

Two of the basic elements in designing monitoring and evaluation plan is allocating reasonable budget and preparing a locally adapted indicators and instruments for data collection and analysis. MENA official has pointed out that, due to the importance of monitoring and evaluation it has a locally adapted indicators. Also, it is mentioned that for the monitoring and evaluation activity, MENA allocated 5-7% of the total budget of the program. As evaluation is not conducted, budget allocated for it is not utilized for the stated purpose.

Monitoring and evaluation is not left solely to the project implementing agency. It needs the support of stakeholders and particularly organizations like those perusing coordination and controlling HIV/AIDS prevention care and support programs. In line with

[3] Mutual local help associations in Ethiopia formed mainly to help each other at times of funeral

this assumption, the officer was asked what assistance MENA is obtaining from HAPCO. The MENA officer remembered, the fund allocations and trainings from HAPCO. Expressing his office concern on the importance of monitoring and evaluation, HAPCO's expert mentioned, MENA is assisted with experts, fund and training to make timely and standardized monitoring and evaluation activities. The researcher has had an opportunity to observe some of the training manuals produced, power point presentations, and training reports.

The MENA official was also interviewed on ways of communicating monitoring and evaluation to stakeholders and other concerned bodies like policy makers, community members and program participants. MENA uses the annual meeting program to disseminate the overall program implantation and results achieved.

The interview on monitoring and evaluation program showed that though MENA has developed and adapted locally applicable indicators and some amount of budget to effect monitoring and evaluation, however, it has not committed itself to make evaluation and in communicating the results to stakeholders.

CHAPTER FIVE

5. DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1. DISCUSSION

As mentioned in the methodology section, a total of 20 subjects (nineteen from MENA and one from MAPCO) were included in the study. Employing qualitative data sources, the study provided a review and evaluation of 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 PLWHA 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 care and support services in such a resource constrained setting. However, the review and evaluation 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 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, discussions held with FGD participants and the interview held with MENA official and beneficiaries' representatives 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 PLWHA and orphans, FGD participants and key informants revealed that meaningful protection of human rights of people infected and affected by HIV/AIDS, legal supports by the Kebele(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 PLWHA and orphans. This gap could also be attributed to the network MENA has with the local Kebele administration. However, the case is crucial and needs further strengthening and improvement.

Regarding the stigma and discrimination they are facing, FGD participants revealed that, PLWHA 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. FGD 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.

Focus group discussants and beneficiaries' representatives 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 PLWHA 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 FGD and interview, participants showed greater interest to participate in

their programs. Literatures also favor the greater involvement of PLWHAs 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 FGD and 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 PLWHA and orphans to its level best with the existing resources. Interviews held with beneficiaries' representatives 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 PLWHA 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 FGD 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 PLWHAs. The feeling of acceptance will further helps 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 FGD and interview findings indicate that home care and clinical services are found to be the other strength of the association. 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 PLWHAs have better concerns by others. This implies, the medical services provided in MENA help to improve the psychological make up of the beneficiaries.

The interview with MENA official disclosed that there are about 150 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'

representatives, 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. One of the FGD participants said also 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. He said there is nothing that makes you happy than improving the situation of a dying person. These all imply that people would have been dead if they are not given support on time. The medical and home care services together are found crucial in changing the quality of life of PLWHA. These activities are among the others that help MENA to meet its goals and objectives.

Care and support is given in a continuum. VCT service is an entry for this service. MENA has no VCT service. As presented in the findings section, FGD participants came to MENA without having proper counseling and testing. Some were even given testing without their consent. In their view, FGD participants noted that they were living without having meaning of life because of improper counseling. Also it is revealed that most PLWHAs were not able to get timely linkage with the care and support services that help them to manage problems earlier. With this regard, MENA has been doing lots of efforts to improve the already damaged psychosocial wellbeing of the beneficiaries. Therefore, the absence of VCT service in MENA puts a lot of burden on MENA's intervention. The existence of such problems and the care and support services call for the establishment of VCT service in providing comprehensive care and support services.

One of the FGD 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 PLWHA 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 PLWHAs should be taken as the most and the foundation of all strengths of MENA.

Assessing the over all potential of the association the officer in MENA has inquired the establishment of full-fledged VCT services in the association and has been confident of the capacity of the association to run all VCT service attaining the standards of quality service. Based on these important indications, the researcher has developed VCT project pertinent to MENA situation while taking course on advanced counseling skills.

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 PLWHA, 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 care and support programs of MENA. FGD participants and beneficiaries' representatives mentioned that the bad situations of PLWHAs improved right after they get membership status

to MENA. To summarize this finding, MENA's care and support is improving the quality of life of PLWHAs 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 PLWHA support groups. In regard to this support, the researcher is confident enough to say if any PLWHA 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 review and evaluation enabled to see MENA's intervention in improving the situations of the members of the association, subjects interviewed and those participated in FGD 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 unmeet 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. The review and evaluation 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 PLWHA associations
- facilitation of obtaining supports from each other by organizing and assisting PLWHA 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 PLWHAs via provision of professional homecare services and medical/clinical supports
- assisting PLWHAs 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 review and evaluation 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 VCT needs of persons are not attained fully as the VCT laboratory service is not available in MENA. This also showed delay in accessing of beneficiaries to their timely needs across the continuum of care and support provisions
    - the stigma and discriminations problems both orphans and PLWHA 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 Kebele 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 Kebele 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 VCT service and its link with the existing care and support services
- 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 PLWHA support group
- acceptance of all PLWHA 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 of the review and evaluation it is also possible to conclude that the services that MENA has significant budget constraints to provide comprehensive case and support services and hence MENA could not fully meet its goals and objectives.

5.3. RECOMMENDATIONS

Based on the findings and assessment of the evaluation some recommendations 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 care and support programs of MENA has made a significant contribution in improving the quality of life of PLWHAs 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 PLWHA 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 PLWHAs 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 PLWHAs 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 PLWHA and orphans found as legal support and attainment of human rights. This support is crucially needed from Kebele's and the community. With this regard, MENA should lay strong network with Kebele and community based organizations like idirs, mahbers, religious associations, etc., to deal and assist PLWHAs 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 absence of VCT service in MENA has shown significant impact in rendering services in a continuum of care and support provision. The existence of other elements of care and support services required the establishment of laboratory for HIV test. Besides, the significant improvements observed through offering the psychological services and the high demand and

request of the beneficiaries calls for the urgent establishment of this VCT service or looking or advocate for an alternative for the use of other organization's VCT services.

5. The existing 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 supports. 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.
6. 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 effect 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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ANNEXE 1

Beneficiaries' Representatives Interview Guide

Good morning. My name is Dawit Tatek. I am studying ways of improving the care and support program of Mekidim Ethiopia National Association .The objective of the study is to review and evaluate the care and support program of MENA in making a difference on the lives of persons living with and families affected by HIV/AIDS.

As part of the assessment, I am going to talk to the concerned bodies, including MENA officials and HAPCO officials. I would use the information I generate to full fill the requirement of the MSW degree and to show MENA its effort in addressing the identified care and support needs PLWHA and orphans The information I collect will not identify you in any way all information you provide will be kept confidential and there will be no negative consequences for your participation in this study and I request your consent to for your willingness.

Thank you for agreeing to be part of this.

1. Name of Organization: _____
2. Address: _____
3. Telephone/Fax: _____
4. E-Mail: _____
6. Identity of Persons Interviewed and Titles: _____

_____

_____

Questions

1. What is the extent of clients participation in the program designing, implementation and monitoring and evaluation? Please tell us how you would like to be involved in the program.
2. How do members of MENA feel and responded the care and support services intervention of MENA?

3. What are the differences observed because of the care and support interventions?
4. What are the limitations of the care and support programs of MENA? How could they be addressed in future activities?
5. What are the successes/ strengths of Mekidim National Association in its care and support programs from your perspective?
6. Are any clients groups underserved or refused by the association (i.e., poor, elderly, women, persons with disabilities, gays/lesbians, or other vulnerable groups)? How does this occur?
7. Are resources and supplies sufficient for providing basic care and support services
8. What are the most frequently reported complaints from MENA care and support interventions ? which of them are improved and which others are still needing improvement
9. What are also the claimed sources of these complaints from the general beneficiaries perspective?
10. What are the lessons to be learned from MENA care and support interventions that the implementing agency can use in future projects?
11. How do you perceived staff attitudes towards beneficiaries and vice versa?.

ANNEXE 2

Focus Group Discussion Guide

Date of FGD_____

Venue_____

Age range of participants_____

Sex of participants_____

Time FGD started_____

Time FGD ended_____

My name is _____ and my colleague and I are gathering information on the care and support program of Mekidim Ethiopia National Association .The objective of the study is to review and evaluate the care and support program of MENA in making a difference on the lives of persons living with and families affected by HIV/AIDS. As part of the assessment, I am talking to the concerned bodies , including HAPCO officials ,MENA officials and beneficiary representatives. I would use the information I generate to full fill the requirement of the MSW degree and to show MENA its effort in addressing the identified care and support needs of persons living with and the family. The information we collect will not identify you in any way and there will be no problems for associated with your participation in this study.

1. What are the common needs/ major problems facing of persons living with HIV/AIDS and AIDS orphans? Which are the most essentials? Who do you think are most needy for the care and support program of MENA.

Probe:

• Care needs (e.g., medical, psychosocial)

• Support needs (e.g., shelter, food, clothing, education)

2. What are the care and support services you are obtaining from the association care?

- Clinical care

- Psychological support
- Socioeconomic support
- Human rights and legal support

3. Which of your needs are properly addressed by the association and which provisions brings change in your life/ situation? What are these changes? Do you think that PLWHA and orphans are getting optimum care and support from the association?

4. What do you think are the best ways to provide care and support provisions for PLWA and orphans?

5. Which area of care and support provision of the association need improvement? How can these existing services be improved?

Probe:

- Community actions
- Organizational actions
- Government actions

6. What is the extent of your participation in the program designing, implementation and monitoring and evaluation? Please tell us how you would like to be involved in the program.

8. What is the procedure of accessing beneficiaries to their best needs in the organization? Are you satisfied with the procedures?

7 . How do you perceive the VCT services you had and its importance to the care and support activities? What is your overall reaction to MENA's counseling services?

8. In general, what is the attitude of beneficiaries towards the care and support programs of MENA and its role?

9. Are there any other comments that anyone of you would like to make about the provision of care and support by the association?

ANNEX 3

Interview Guide with MENA Official

Good morning My name is Dawit Tatek . I am studying ways of improving the care and support program of Mekidim Ethiopia National Association .The objective of the study is to review and evaluate the care and support program of MENA in making a difference on the lives of persons living with and families affected by HIV/AIDS.

As part of the assessment, I am going to talk to the concerned bodies, including beneficiaries, beneficiaries' representatives and HAPCO officials. I would use the information I generate to full fill the requirement of the MSW degree and to show MENA its effort in addressing the identified care and support needs PLWHA and orphans. The information I collect will not identify you in any way all information you provide will be kept confidential and there will be no problem for your participation in this study.

Consent

I'm going to ask you some questions related to care and support programs of MENA, which some people might find them difficult to answer. Your answers are completely confidential. Your name will not be written on this study. Your honest answers to these questions will help us better understand the care and support provisions to improve the services in the future.

_____ Agreed

_____Not agreed

Signature _____

Date_____

1.Name of Organization_____

2. Address _____

3. Telephone/Fax_____

4. E-Mail_____

5. Identity of Persons Interviewed:

- Name _____
- Age ____ Sex_____ Title _____
- Service year in the program_____
- Education level_____
- Special training relevant with current position _____

Interview question

1. Organization's programs and services

- What are the basic services exist in the association for PLWHA and orphans? Who receives them, in what condition, for how long?
- Are the services consistent with the goals and objectives of the program?
- What standards for quality of services have been established?
- How communication patterns between management, supervisors, and line staff influences services.

2. Voluntary Counseling and Testing

- Do MENA provides VCT to all beneficiaries needing the service. How well do counselors meet clients' needs? How do you feel measure the association's capacity and condition to provide basic HIV counseling and testing and to manage HIV/AIDS clinical services?.

3. Clinical services & management

• Are there trained staff to manage HIV-related illnesses, manage referrals for HIV-infected patients, and supervise palliative care.

- 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. Support

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

• 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

- What type of client groups does this association serve?
- Are any clients groups underserved or refused by the association (i.e., poor, elderly, women, persons with disabilities, gays/lesbians, or other vulnerable groups)? How does this occur?
    - 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? Have you also assessed the process of this referral?

6. Monitoring and Evaluation

- How is Monitoring and evaluation planed and designed?
- How often is Monitoring and evaluation taken? How often reports prepared periodically?
- How much percent of budget from the total project budget allocated for monitoring and evaluation?
- Are there locally adapted Monitoring and Evaluation indicators and instruments for data collection and analysis?
- Is there any assistance by the government to enhance the capacity of MENA in Monitoring and Evaluation of care and support program.
- Is there a way of communicating Monitoring and evaluation results to stakeholders, policy makers, beneficiaries, community members and program participants?
- **7. Miscellaneous**
- 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.
- What are the strengths and limitations of the care and support programs of MENA?
- What out comes observed because of this program? what do these outcomes mean
- Does the care and support program make a difference? What are these differences?

ANNEX 4

Interview Guide with HAPCO Official

Good Afternoon. My name is Dawit Tatek. I am studying ways of improving the care and support program of Mekidim Ethiopia National Association .The objective of the study is to review and evaluate the care and support program of MENA in making a difference on the lives of persons living with and families affected by HIV/AIDS.

As part of the assessment, I am going to talk to the concerned bodies, including MENA officials and beneficiary representatives. I would use the information I generate to full fill the requirement of the MSW degree and to show MENA its effort in addressing the identified care and support needs of PLWHAs and orphans

I'm going to ask you some questions related to HAPCO's support to MENA's care and support programs for persons affected by and infected with HIH/AIDS, which some people might find them difficult to answer. Your answers are completely confidential. Your name will not be written on this study. Your honest answers to these questions will help us better understand the government supports to the care and support provisions and to improve the services in the future.

_____ Agreed

_____Not agreed

Signature _____

Date _____

1. Name of Organization_____
2. Address _____
3. Telephone/Fax _____
4. E-Mail_____
5. Identity of Persons Interviewed:

- Name _____
- Age ____ Sex_____ Title _____
- Service year in the program _____
- Education level_____
- Special training relevant with current position _____

The questions

1. What are the specific policies, strategies and guidelines of the government regarding the care and support of People living with HIV and orphans?

2. How the government is involved in implementing these polices strategies and guidelines in the country particularly by NGOs like Mekidim Ethiopia National Association.
3. What efforts and measures are in place to ensure effective implementation and monitoring of existing policies?
4. What programs does your office have in place to support PLWHA and orphans?
5. What programs does your office have in place to organization like Mekidim National Association in general and to its beneficiaries, PLWHA and orphans in particular?
6. Is there any assistance by the government to enhance the capacity of MENA in Monitoring and Evaluation of cares and support program.

ANNEX 5

Observation Tools

1. Home visits

Homes of Five home care beneficiaries (Three PLWAs & two Orphans) 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 them selves and with the organization
- Treatment and handling of the beneficiaries with respect to human rights and legal needs

Declaration

I, the undersigned, declare that this thesis is my original work, has never been presented in this or any other university, and that all resources and materials used herein, have been duly acknowledge.

Name: Dawit Tatek

Signature _____

Place: Addis Ababa University, Ethiopia

Date of Submission:_____

This thesis has been submitted for examination with my approval as a University advisor.