RESEARCH AND GRADUATE PROGRAMS

Exploring the Role of Community Based Organizations Specially Idirs in Mitigating the Spread of HIV/AIDS in Adama Town

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LIST OF ACRONYMS

AIDS	-	Acquired Immunodeficiency Syndrome
ART	-	Antiretroviral Treatment
BCC	-	Behavior Change Communication
CBO	-	Community Based Organization
CG	-	Care Givers
CSA	-	Central Statistics Agency
DHS	-	Demographic and Health Survey
FDRE	-	Federal Democratic Republic of Ethiopia
FGAE	-	Family Guidance association of Ethiopia
HAPCO	-	HIV/AIDS Prevention & Control Office
HCBC	-	Home and Community Based Care
HIV	-	Human Immunodeficiency Virus
IEC	-	Information, Education, and Communication
MOH	-	Ministry of Health
NGO	-	Non-Governmental Organization
OIs	-	Opportunistic Infections
OVC	-	Orphan and Vulnerable Children
PLWHA	-	People Living with HIV/AIDS
PMTCT	-	Prevention of Mother-to-Child Transmission
STI	-	Sexually Transmitted Infection
UNAIDS	-	Joint United Nations Program on HIV/AIDS
UNICEF	-	United Nations Children's Fund
VCT	-	Voluntary Counseling and Testing
WHO	-	World Health Organization

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Abstract

This study was conducted to explore the role and contribution of Idirs in combating HIV/AIDS through Home and Community Based Care (HCBC) programs in Adama town. Idirs are traditional community based organizations (CBOs) primarily established to facilitate burial ceremonies and comforting the bereaved. With the advent of HIV/AIDS pandemic, the role of Idirs has transformed from such single communal functions to HIV/AIDS prevention and control. Ten Idirs in Adama have been implementing HCBC program to improve the quality of life of bed-ridden patients and their families. The study employed qualitative research method. Three Idirs that included in the study were selected randomly. After the three Idirs identified, the research participants were selected using purposive sampling technique. The qualitative data gathering instruments included in-depth interview, focus group discussion and observation. Subjects of the study include program beneficiaries, voluntary care givers and Idirs HCBC committee members. Key informant interview also was carried out with government and non-government organizations representatives. The study involved strict respect for informed consent, voluntary participation and confidentiality. The findings of the study indicated that Idirs HCBC program has significantly contributed to improve the life of bed-ridden patients. Despite the important work of Idirs HBCB program, patients expressed unmet needs. Hence, insufficient nutrition support, housing problem, and care for AIDS orphans were major challenges of the program. The study recommended the strengthening of HCBC program referral chain, local resource capacity, protecting and care of AIDS orphans and intervening in income generating activity (IGA) and integrating family planning services with HIV/AIDS prevention.

CHAPTER ONE

INTRODUCTION

Back Ground and Problem Statement

Background

The land area of Ethiopia is estimated at about 1.1 million square kilometers and the population of Ethiopia is estimated to be 77.4 million, of which 44 percent of the population is below the age of 15 (Population Reference Bureau, 2005). Eighty-five percent of the population is living in rural areas and agriculture is the main pillar of the economy. The country is characterized by high population growth; low economic development, highly dependence on subsistence agriculture, high prevalence of HIV/AIDS, and poor infrastructure.

HIV/AIDS is a threat that impedes the overall development endeavors of the country. The virus affected and infected all members of the community including women, children and productive citizens of the country, young people. The government has formulated a number of policies and legislative frameworks that help to prevent and control HIV/AIDS. Despite all the positive and encouraging activities in policy formulation, the implementation of the laws is much more challenging. However, the contribution of institutions, associations and community members to mitigate the impact of HIV/AIDS is important.

This proposal is designed to explore the role of community based organizations (CBOs) especially Idirs[1] in combating HIV/AIDS in Adama Town. Particular emphasis has given to the contribution of Idirs on providing care and support for people living with HIV/AIDS (PLWHAs). I have selected the community based organizations (CBOs) due to their effort being made to mitigate the spread of HIV/AIDS and improve the wellbeing of PLWHAs and orphan children. In addition, Idirs role in mitigating the spread of HIV/AIDS is not adequately explored and documented. Therefore, this study will motivate other researchers to conduct study in the area.

Family Health International (FHI) training module (September 2004, P.8), used the March 2001 Gaborone Declaration to define community home-based care as:

> Care given to an individual in his or her own natural environment by his or her family and supported by skilled social welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs.

Accordingly, 10 Idirs in Adama town have recruited, trained and deployed voluntary care-givers to give home and community based care for bed-ridden patients.

In addition, writing a thesis is a requirement for the partial fulfillment of Masters Degree in Social Work (MSW) at the Addis Ababa University. Therefore, the thesis has a mission of fulfilling this partial requirement. The data collection techniques of the study were focus group discussion, in-depth interview, observation and document review.

Problem Statement

Ethiopia is the second most populous country in Sub-Saharan Africa. Though Ethiopia constitutes only 1% of the world's population, it contributes about 9% of the world's

[1] Idirs are community based traditional organizations established by members voluntarily. Idirs are primarily established to provide burial services to their members and relatives and are known as traditional burial societies. Membership in Idirs is on a voluntary basis.

HIV/AIDS cases. It is estimated that about 1.5 million people are infected with HIV/AIDS making Ethiopia the third highest in Africa (UNAIDS, 2004). The growth of the epidemic in Ethiopia has been and continues to be rapid. For instance, according to the Ministry of Health (MOH) report the national HIV prevalence was estimated to be 3.2 % in 1995, 4.1 % in 2001, and 4.2 % in 2002, and the figure has increased to 4.4 % in 2003 (MOH, 2004).

Thus, the impact of HIV/AIDS in Ethiopia has been devastating. It is more pronounced in adult age group of 15-49. Data organized by the Ethiopian MOH for ten years also indicates 90% of AIDS cases occur to adults between the ages ranging 20 to 49 (MOH 1998, p.13). According to the 1994 national population census, the economically active segment, between ages 15 and 49 of the population is about 44% of the total population (CSA, 1999). AIDS accounts for 30 % of the adult death that happened in Ethiopia in the year 2003 (MOH, 2004, P.23). The same source indicates that the cumulative number of AIDS deaths is estimated to increase from about 350,000 in 1998 to 6 million by 2014. The death of this economically active group leaves the country with long lasting development problems.

The MOH 2004 report estimated that a total of 4.6 million children under 17 in the country are estimated to be orphans for various reasons, of which 536,720 were AIDS orphans in 2003. A considerable number of these orphans are reported to live outside their family environment and are faced with environmental, physical and social hazards.

In addition, 120,000 adults and children were estimated to have died of AIDS in Ethiopia during 2003 (UNAIDS, UNICEF & WHO, 2004 Update). As a member of the community, I have observed that at family level there is an increased burden and stress for the extended family. Many grandparents are left to care for young children. Some families are headed by

children. This shows that there is a tremendous strain on social systems to cope with such a large number of orphans given the poverty situation in the country. The cumulative number of people living with HIV/AIDS and orphaned children needing care and support is challenging. The impact of AIDS on children is complex and encompasses material hardship and psychological distress.

In Ethiopia, an estimated 60 to 80 percent of health problems are due to infectious and communicable diseases and nutritional problems. These easily preventable infectious diseases are attacking the healthy life of the community. In addition, the health service coverage in the country is very low and most health institutions are concentrated in urban areas. In 2003/04, the number of hospitals, health centers and health stations in the country were 126, 519 and 1797, respectively. The report further stated that, during the same period, the number of health professionals at service in the country was: physicians' 1,996, health officers 683, nurses 15,544, health assistants 6,628 and Para medicals 5,215 (MOH, 2003/2004). The data clearly shows that health professionals' ratios to the population have a significant gap and shortage. Therefore, for the 71 million population of Ethiopia, in 2003/04 the ratio of health professionals to the population was, physician 1:35,604, Health Officer 1:104,050, Nurse 1: 4,572, Health Assistant 1:10,722 and Para Medicals 1: 13,627.

The health needs of the community are more critical due to the spread and impact of HIV/AIDS pandemic. HIV/AIDS patients make recurring visits to health institutions for various health services and treatment. In addition, due to the nature of the disease, AIDS patients use hospital beds for a longer time. For instance, in 2002/3 AIDS patients occupied 57 percent of hospital beds in Addis Ababa (MOH, 2004). In general, the frequent visits of AIDS patients to health institutions and that they occupied hospital beds for longer period of

time affected the types and quality of services rendered in health institutions. One of the key solutions that is proposed and used to solve such types of problems is the initiation and implementation of home and community based care (HCBC) services to patients in their home environment in a systematic and sustainable manner. For this purpose, the involvement and contribution of traditional community based organizations that are established by the full consent and resource of the community is indispensable.

Significance of the Study

I have selected to explore the contribution and role of community based organizations, especially Idirs, which are working to reduce the threat of HIV/AIDS in Adama town. Primarily, Idirs were established for the sole purpose of facilitating funeral services and mourning during the death of a family of Idir members. In Ethiopia the involvement of Idirs in such HIV/AIDS prevention and control activities is a new venture that has to be studied to strengthen and replicate home and community based care and support programs. Idirs participation in protecting, preventing and promoting the well being of the community especially those who need care and support is a new undertaking that has to be studied and promoted. It is uncommon to found a study conducted on the contribution of Idirs towards mitigating the spread of HIV/AIDS.

Therefore, the study is important to encourage further study, practical action and documentation of best practice. The research is crucial to explore best practice, lessons learned, challenges and knowledge and information gap of home and community based care program of Idirs. In addition, for the student of Social Work, exploring the response of

community-based organizations to mitigate the crushing impact of HIV/AIDS is an important undertaking.

Objective of the Study

General Objective

The overall objective of the study was to examine the role and function of community based organizations (Idirs) in reducing the HIV/AIDS problem in Adama town.

Specific Objectives

- Investigate the types of care and support services provided to people living with HIV/AIDS;
- Identify the actual challenges faced by people living with HIV/AIDS and the responses of Idirs in Adama town;
- Explore the level of collaboration and linkage of Idirs with other stakeholders and community mobilization efforts;
- Highlight some of the impacts of Idirs services on the quality of life of PLWHAs in the town;

Research Questions

The research was designed to address the following research questions.

- What motivated Idirs to work on HIV/AIDS and how they address the problem of HIV/AIDS?
- What is the contribution of Idirs in the town to mitigate the spread of HIV/AIDS and improving the life of PLWHAs?

- Do the care and support services tailored to the needs of beneficiaries?
- How the activities of Idirs are linked (networking and partnership) with other pertinent institutions?
- What are the feelings, attitude and reaction of beneficiaries, Idirs members and the community towards the services provided by Idirs?
- What are the challenges encountered, best practices and documentation process?

Strengths and Limitations of the Study

Strengths

There was no previous study conducted to explore the contribution of community based organizations/Idirs in mitigating the spread of HIV/AIDS through home and community based care. Therefore, this study will provide information to similar studies that are going to be conducted in the future. Additionally, it may provide a clue for social workers to intervene in the area of HIV/AIDS prevention and control, community mobilization and community based organizations and voluntary contributions.

Limitations

The study used purposive sampling technique and therefore does not claim to be representative of all Community and Home Based Care programs.

Definition of Terms

Home and Community Based Care: Care given to an individual in his or her home environment by his or her family and/or voluntary care givers supported by skilled

professionals and communities to meet physical, health, spiritual, material, and psychosocial needs of patients.

Idirs: Idirs are traditional community based organizations established by members voluntarily. Idirs are primarily established to provide burial services to their members and relatives and are known as traditional burial societies.

Voluntary Care Givers: trained voluntary workers recruited and deployed by Idirs to provide home and community based care to bed ridden patients.

PLWHA: an individual who is living with HIV or having signs and symptoms of AIDS

An orphan is a child who is less than 18 years and who has lost one or both parents, regardless of the cause of the loss.

Vulnerable child is a child who is less than 18 years of age and whose survival, care, protection or development might have been jeopardized due to a particular condition, and who is found in a situation that precludes the fulfillment of his or her rights.

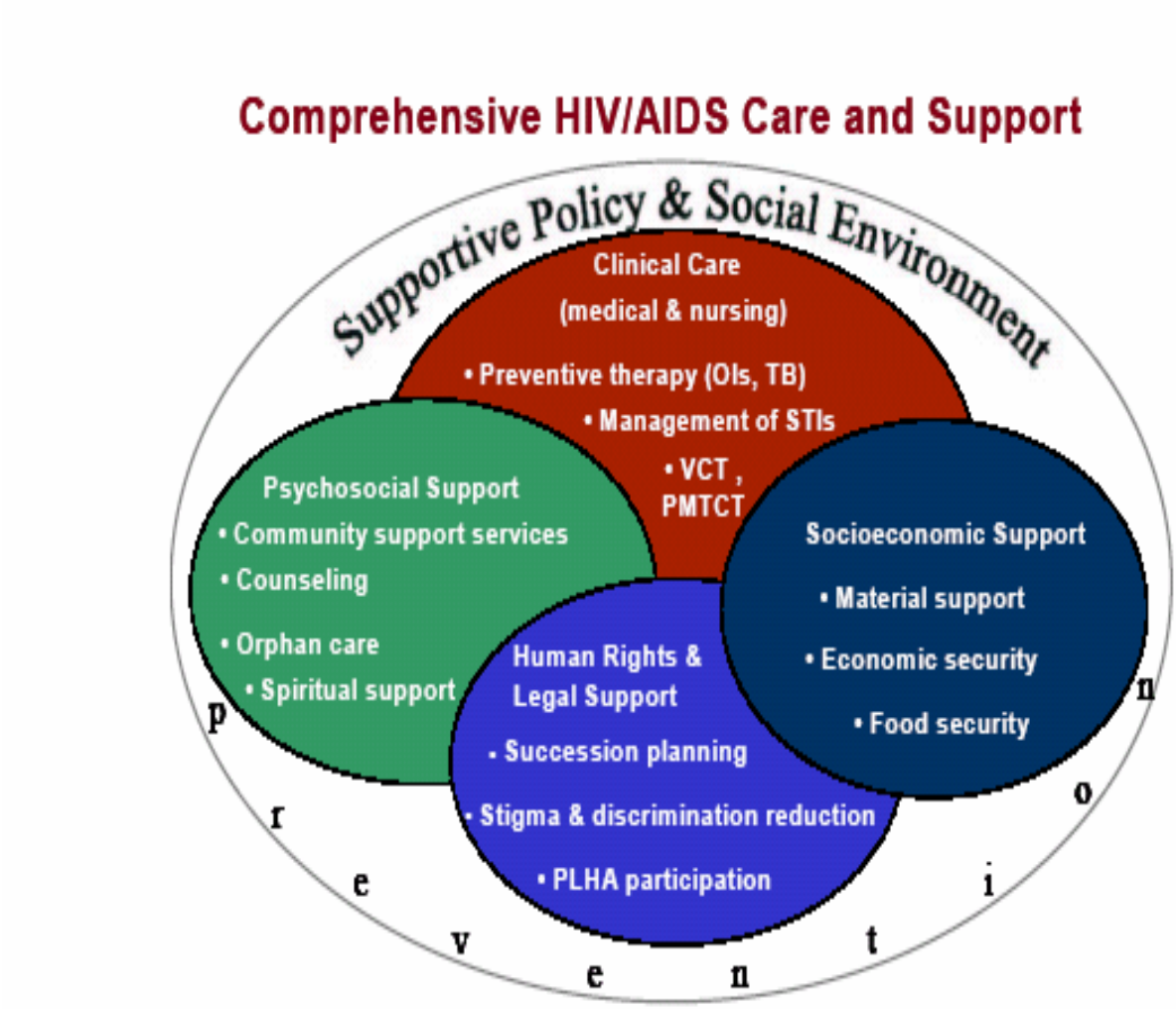
Conceptual Framework

Home and community based care is the main component of HIV/AIDS prevention and control strategy designed to improve the life of PLWHAs and their family members. In addition, the HCBC program has significant contribution to mitigate the spread of HIV/AIDS. HCBC strengthened the prevention, control, and care and support synergy.

The diagram below indicates HIV/AIDS care and support program should integrate various services to reinforce each other for the effective, efficient and successful program implementation. It is possible to understand that one institution or program could not give a full-fledged service to bed-ridden patients independently. The diagram therefore further

stated the need of supportive social policy for the implementation of HCBC program. It also denotes that HCBC should be linked to prevention and care program to strengthen the continuum of care. Therefore, the diagram shows the conceptual framework of the HCBC organization and its close linkage and chain with health facility and PLWHAs support group and referral services. The framework further highlights the importance of integrating community and facility based services to strengthen continuum of care. In addition, the diagram clearly indicates the essential role of HCBC program in the HIV/AIDS prevention and control efforts.

Hence, home and community based care has a significant role for HIV impact mitigation, prevention and control. Therefore, in order to explore the role of idirs in mitigating the spread of HIV/AIDS in Adama town through the HCBC program/services data was gathered using qualitative methods. The study, therefore, explored the immediate and long-term impacts of these Idirs HCBC program. Thus, in-depth interview and focus group discussion were conducted with HCBC program beneficiaries, voluntary care givers and Idirs HCBC committees and pertinent stakeholders. Moreover, data was collected using direct observation on the situation of patents and document review.



Source: Family Health International 2005

CHAPTER TWO

REVIEW OF LITERATURE

Magnitude of HIV/AIDS

In the Ethiopian community, HIV/AIDS is now a leading cause of morbidity and mortality. In addition, it has a significant impact on the overall development efforts of the country. Its socioeconomic impact ranges from affecting the life of individuals to the disorganization and dissolution of households and families. According to the MOH report (2006), it is estimated that 1.3 million people in Ethiopia are living with HIV. The HIV adult prevalence rate at national level is 3.5 percent, which is 10.5 % in urban and 1.9% in rural areas.

Adama is located in the Oromia Regional sate. According to the Ministry of Health (MOH) AIDS in Ethiopia 5th report (2006), the HIV adult prevalence rate for Oromia region is 2.4% where as in Adama town HIV adult prevalence rate is 9%. The HIV prevalence rate in Adama is very high compared to the prevalence in the region.

Impact of HIV/AIDS

The HIV pandemic has a major impact on the social, economic and cultural life of the community. HIV/AIDS is affecting productive citizens of the country. One of the major consequences of HIV/AIDS is increasing number of mortality. The estimated number of AIDS deaths in the country in 2005 was 134,450, which means 368 persons a day (MOH, 2006). In Ethiopia, Population between the age group of 15 to 49 constitutes 90 percent of the AIDS cases (MOH, 2006). This age category is the most productive and resourceful part

of the population. Most literate and experienced members of the community that are involved in agriculture, education, health and other development sectors affected by AIDS means the socioeconomic development of the country is in vain.

Similarly, as a result of AIDS the number of orphans in the country is increasing. In 2005, it was estimated that there were a total of 4, 885,337 orphans aged 0-17 years. Of these, 744,100 were AIDS orphans (MOH, 2006 P. 25). In addition, HIV/AIDS has a significant impact on the overall development efforts of the country. The HIV/AIDS epidemic has placed a large burden on government health facilities that are already functioning with limited resources.

The impact of HIV/AIDS on Idirs is not negligible. Some Idirs were in problem to cover the cost of funeral service and other mourning expenses when members or their families died. Some Idirs dissolved due to their inability to pay for funeral services, due to increased deaths and members' failure to pay monthly contribution.

The other major problem of HIV/AIDS is the high prevalence of stigma, discrimination and isolation affected PLWHAs and their family members. 2002 World AIDS Day motto was "Fight Stigma and Discrimination" and "Live and Let Live". It is celebrated worldwide and the theme shows how stigma and discrimination is a serious issue all over the world. The UNAIDS, in this regard, discusses the problems associated with stigma and discrimination to show the severity of the problem stating that:

> Stigma and discrimination associated with HIV /AIDS are the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact. HIV/AIDS-related stigma and discrimination are universal, occurring in every country and region of the world. They are

> triggered by many forces, including lack of understanding of the disease, myths about how HIV is transmitted, prejudice, lack of treatment, irresponsible media reporting on the epidemic, the fact that AIDS is incurable, social fears about sexuality, fears relating to illness and death, and fears about illicit drugs and injecting drug use (UNAIDS, June 2002: 5).

In general, HIV/AIDS has imposed economic, social, and health problems in the country.

Policy Environment on Care and Support

Ethiopia adopted the HIV/AIDS policy in August 1998 to emphasize prevention, care and support that target vulnerable groups. One of the specific objectives of the HIV/AIDS policy in Ethiopia is the promotion of proper institutional-, home- and community-based health care and psychosocial support for people living with HIV/AIDS, orphans and surviving dependents (FDRE, August 1998). To realize this objectives the government has designed, in its HIV/AIDS policy, a general implementation strategy of medical care and psychosocial support, which states that, "government institutions, non-government organizations, religious organizations, bilateral and multilateral agencies, private sectors, community based institutions and the community at large shall be mobilized to support people living with HIV/AIDS and affected family members. Special attention shall be given to people who are abandoned and helpless" (*Ibid*: 31).

The government has developed the first strategic framework for five years (2000-2004) for national response for HIV/AIDS and updated the strategic framework for another five years (2004-2008) period. The policy has included the safety of family especially the issue of children who are vulnerable and orphan due to HIV/AIDS. The general policy issues that are adopted in the document are: -

- Reinforce the implementation of effective measures to prevent and control the spread of HIV/AIDS;
- Make the necessary provision of care and support to people living with HIV/AIDS and their affected family members;
- Strengthen the collaborative efforts with regional and international organizations for the prevention and control of HIV/AIDS;
- Ensure the protection of the human rights of people living with HIV/AIDS;
- Provide health care to people living with HIV/AIDS on a scheme of payment according to ability with special assistance for those who cannot afford to pay;
- Promote researches and studies on HIV/AIDS and make use of the outcome for preventive, curative and rehabilitative purposes;
- Develop the capacity to detect the HIV infection and its spread in the community through testing and disease surveillance systems; and
- Promote integrated coordination of government, NGO's, Private sectors for the prevention and control of HIV/AIDS (FDRE, 1998: P. 25-26).

Moreover, the second strategic plan (2004-2008) has emphasized PLWHAs and orphans and other vulnerable children as special target groups. One of the main strategies stated in the document is "promote care within the family and mobilize the community to address and accommodate the issue of People Living with HIV/AIDS and orphan and vulnerable children through traditional and extended family mechanisms" (HAPCO & MOH, 2004, P.15). Ethiopia adopted home-based care as a strategy and issued national guidelines in 1996 and 2001 (MOH, 2002) to help organize these services and prepared a training manual in 2002. The aim of the handbook is to provide health care workers with the information

they need to help families gain confidence about their own ability to give safe, compassionate and helpful care to people with AIDS in their homes. The handbook is therefore revised and designed in order to suit the specific health needs of people with AIDS in the Ethiopian context (MOH, January 2002).

Skills' training is included as one component of care and support for people living with HIV/AIDS. This component is included in the general strategies of the HIV/AIDS policy as: "Efforts shall be made to create self supportive and income generating opportunities for people living with HIV/AIDS as the need arises" (FDRE, 1998: 31).

According to Yimane B. & et al (2006) appropriate and sustainable home and community based care and support service was important as a result of the rapidly increasing number of AIDS cases in Ethiopia and the over occupancy of hospitals. It further explained the services should involve mainly families and faith-based institutions, NGOs and private institutions.

As a result, several institutions and associations including individuals are working to avert the HIV/AIDS problem and to improve the quality of life of people living with HIV/AIDS and orphan and vulnerable children (OVC).

Efforts Being Made to Avert the Problem

HIV/AIDS is a serious development problem that needs the concerted effort of all stakeholders. Accordingly, considerable effort has been made to prevent and control the spread of the virus based on the national intervention strategies. Among other things, care and support to the infected and affected persons was the priority intervention implemented in the country. The behavioral change communication and information dissemination activities, making antiretroviral drugs (ART) freely available, prevention of mother to child

transmission (PMTCT), condom promotion and distribution, voluntary counseling and testing (VCT) and STI diagnosis and treatment services are among others undertaken to curb the spread of HIV/AIDS. Community mobilization and active involvement of people living with HIV/AIDS through their association has a central place in the fight against AIDS and its impact. In addition to different efforts to avert the problem, PLWHAs themselves established their Association in the country. The contribution of faith based & community based organizations (Idirs), anti AIDS clubs and Associations established by the community at grass root level is paramount. It is also important to acknowledge the financial and technical assistance of the international community in the fight against AIDS.

Africa region working paper on HIV/AIDS (Mohammad N & Gikonyo J., 2005) pointed out the great need for services and support provided by community home-based care (CHBC) program to persons infected and affected by HIV/AIDS. In Sub-Sahara Africa where the HIV/AIDS epidemic is of paramount concern, the nature of the disease, weak public health infrastructure, increasing health costs, and lack of resources has made community home based care a necessity in the continuum of care in Sub-Saharan Africa. As part of the Sub-Sahara Africa this assertion is true for Ethiopia where large numbers of people are living with HIV/AIDS.

Comprehensive Community-Based Care & Support Guideline of HAPCO (2006, P. 26) for PLWHA, OVC and Affected Families have identified seven packages (areas where support is evident). These include:

(1) Health care and support (medical package);

(2) Food and nutrition;

(3) Shelter and clothing;

(4) Economic;

(5) Psycho-social;

(6) Spiritual;

(7) Legal; and Information, education and communication (IEC)/BCC

The policy further stated the role and responsibilities of social organizations including Idirs in the HCBC program. These include:

- Participate in identifying eligible individuals for support and keep record of same.
- Participate in needs assessment.
- Mobilize resources.
- Make relentless efforts towards empowering households for the use of support services.
- Sensitize the community for the purpose of reducing stigma and discrimination.
- Facilitate networking among and between appropriate units.
- Train and deploy HBC providers.
- Participate in monitoring and evaluation of activities and submit periodic reports to appropriate bodies. (HAPCO, 2006, P. 57).

In the Ethiopian Multi-Sectoral AIDS Program (EMSAP) implementation report it is stated that care and support services were provided to 1,866 PLWHA and 6,714 AIDS orphans living in eight regions. Support services are also provided to elderly people who lost their families due to HIV/AIDS and bedridden patients. The types of services provided are provision of cash assistance, food and shelter in some instances, educational materials and school uniforms for the orphan children (HAPCO/EMSAP, 2001/02). In the report, it is also stated that these care and support services were provided during the year 2001/02. However, the report does not clarify how and by whom the services were provided.

UNAIDS Ethiopia believes that a lot more has to be done towards the care and support of PLWHA. It also believes that, health systems are under funded and overburdened in many developing countries including Ethiopia. Non-governmental and community based organizations, individuals and families are key providers of HIV treatment and care. The need for treatment is rising as increasing numbers of people become infected (UNAIDS Ethiopia, 2002).

Even though, the effort being made so far to avert the problem is encouraging, the HIV/AIDS problem is a serious development crisis that knocks the house of every family and needs sustainable, courageous and dedicated effort of all stakeholders

CHAPTER THREE

THE RESEARCH METHODOLOGY

The Study Area

Adama is located in the Oromia Regional State 100 kilometers away from the federal capital, Addis Ababa. The Population of the town is estimated to be 250,000 (Adama Municipality, 2005). The town is divided in to 14 kebeles[2]. The town is a very important economic hub in the country and an intersection point for many regional cities of the country. Stretched along the main Ethio-Djibouti road that also takes to ports in Somalia; the town has one of the highest commuters and passers-by on daily basis. A minimum of 600 heavy-duty truck drivers pass nights in the town.

The HIV prevalence rate in the town is one of the highest like most urban areas of the country. According to the MOH report (2006), HIV prevalence among pregnant women attending antenatal care in Adama health center was nine percent, which is one of the highest in the region. In such metropolitan town, where trade is dynamic and most people rather engaged in business, concern for home related communal/service activity is a concern. Thus, I have chosen to explore the response of Idirs in Adama town in combating HIV/AIDS, the second biggest town in the country.

Therefore, this exploratory study is focused on Idirs/community based organizations contribution to mitigate the spread of HIV/AIDS in Adama town. There are around 158 Idirs in the town that have established coalition of Adama general Idirs. In fact, there are a few other Idirs that are yet not member of the coalition of general Idirs. The community-based

[2] Kebele is the smallest government administrative unit in Ethiopia.

organizations, which captured the interest of the investigator, are traditional burial societies that were mainly engaged in providing funeral as well as comforting services.

Among the 158 members of the Adama Idirs coalition, ten Idirs have started formally and publicly responding to HIV/AIDS problem. The ten Idirs are working to mitigate the spread of HIV/AIDS and enhance the quality of life of bed-ridden patients that were in need of care and support. These Idirs established partnership program with pertinent civil society organizations to address the HIV/AIDS problem. Idirs decided no more to be a burial society. They rather envisions a society free from HIV/AIDS and involved in awareness rising, home based care and community mobilization activities for support of PLWHA.

Study Design

The study has employed a qualitative research method to explore the contribution of Idirs to enhance the life of PLWHAs. Primary and secondary data collection methods were used to gather data. Therefore, the research methods selected to conduct the study include FGD, in-depth interview, observation and review of secondary sources.

Population for this study comprised of people living with HIV/AIDS and beneficiaries of Adama Idirs HCBC program; voluntary care givers actively involved in providing care and support, Adama Idirs HCBC program coordinating committees and partners who have direct contribution and contact with the HCBC program of Adama Idirs.

Sampling Procedure

All the ten Idirs working on HIV/AIDS prevention and control in Adama town were included in the sampling frame of the research. From among the ten Idirs, the actual sample size was selected using simple random sampling technique. Of the total 10 Idirs, three Idirs

are selected for the study. It is believed that the ten Idirs have similar objectives and activities and the selection and inclusion of three Idirs in the study is representative. The selection of three Idirs to the study was also feasible from time and cost perspective. After the three Idirs identified, the FGD and in-depth interview participants were selected using purposive sampling technique.

Focus Group Discussion (FGD)

FGD is one the major data collection instruments of the study. In total, three group discussions were conducted to collect data, which were believed helpful to explore the contribution of Idirs and the change observed in the life of PLWHAs. Participants of the FGD were Idir leaders, volunteer caregivers and community members/beneficiaries from the three Idirs included in the study. The participants of the FGD were purposively selected from the three sample Idirs. A total of 30 people participated in the three-group discussion. I have facilitated the group discussion as a moderator. The roles of the moderator were stimulating participants to air out their ideas, moderating the time of talkative persons and coordinating the discussion process. An experienced and active note-taker was also assigned to record the points raised by participants. The researcher used audio-tape recorder based on the permission of participants. The play from the tape recorder was instrumental in transcribing most important points of the group dynamics during analysis.

In-depth interview

In depth interview was the other data collection instrument employed in the study. Thirty-six key informants for the in-depth interview were selected purposively. These included 12 beneficiaries/patients of the HCBC service provided by Idirs (four from each of the three Idirs), Idirs HCBC committee members (6), voluntary care givers (9), kebelle administration officials (3), two officials from the City administration HIV/AIDS and

Health Bureau, two partners of Idirs working on HIV/AIDS/ NGOs, and two Health Institutions.

In addition, direct observation method was utilized to observe the beneficiaries situation and understand their feeling about the service delivered by Idirs.

Secondary Data Sources

What is more, document review was the other method utilized to gather data on the contribution of Idirs to mitigate the spread of HIV/AIDS in Adama town. To further enrich the primary data, different documents were reviewed and analyzed. The researcher reviewed by-laws of Idirs, project documents, action plan, budget, periodic report and other relevant secondary data available in their respective office as well as those of partner organizations. The researcher has consulted books, previous research papers, situation reports, relevant articles, journals and magazines to supplement the primary data.

Data Collection

FGD and individual interview checklists were developed for the group discussions and key informant interview purpose. Data collection instruments prepared in English and translated into the local language (Amharic and Oromiffa language). In order to get the comments of the community data collection instruments were pre-tested in a nearby community similar to the target population before the actual work was started. Persons participated in the pre-testing of data collection instruments were excluded as a respondent in this study. Subjects were informed about the objective of the study and respondents gave verbal informed consent to participate in the study.

A written guideline was used for data collection. The guideline was important to ensure degree of standardization in the data collection process. Carefully selected questions geared towards stimulating further discussion were included and thoroughly discussed. Special

attention was given to participants to express their ideas and views about the service delivered by Idirs. In addition, direct observation was made to assess beneficiaries and community reactions to Idirs in relation to the services they rendered.

The FGD was started with the introduction of the facilitator and note-taker and by briefing FGD participants on the objective of the study. Following this, participants had raised questions, which were not clear about the objectives of the study. All participants encouraged to fully take part in the discussion and speak their views. The focus group discussion took on the average 55 minutes. The group discussions were conducted in Idirs office, which was a convenient place for discussion.

The interviewer used audio records after he obtained the permission of the interviewees. Each day's information collected from key informants using interview had been written and finalized the same day to avoid failure to remember the information thus mainstreaming accurate data.

Data Analysis

The data was analysed using qualitative data analysis techniques such as description, explanation and exploration of ideas to identify the theme of the discussion. For that reason, the data was analysed using thematic analysis method. In order to grasp the ideas/information of focus group discussants, the facilitator has emphasised the points raised by participants at the end of each discussion session. The results from FGD were transcribed before analysing the field results. A comprehensive field report was prepared using field notes and transcribed information. The data was analyzed manually.

Ethical Clearance

Ethical clearance was obtained from Addis Ababa University Graduate School of Social Work. The study involved strict respect for informed consent, voluntary participation and confidentiality. All PLWHA respondents had agreed to disclose their HIV status to the researcher. Names and job titles of participants are not included when they are quoted in reports. Privacy, confidentiality and benefits were maintained. Other responsible authorities and community leaders including Idir leaders were informed to get their support and commitment to the study.

Communication of Results

The results of this study will be communicated to different responsible organizations. It will be submitted to Oromia Regional Health Bureau, Oromia Regional HIV/AIDS Prevention and Control Office (HAPCO), Adama general Idirs coalition and to local as well as international organizations who are working in the area of HIV/AIDS prevention particularly on home based care and community mobilization. Efforts will be made to publish the paper in different journals and it will be reserved in the school library for further dissemination.

CHAPTER FOUR

RESEARCH FINDINGS

Background Information

The study was carried out in April and May 2007. Data was collected through face-to-face interview with 12 (6 males and 6 females) HCBC program beneficiaries, nine (3 males and 6 females) care givers, six (4 males and 2 females) Idirs HCBC committee members, and 9 (5 male and 4 female) officials of other partner organizations. Similarly, out of the 30 discussants of the FGD, each ten were patients, care givers and Idir HCBC committee members. Table 1 shows the age distribution of the respondents.

Table 1: Age Distribution of Respondents by category

	In Depth Interview			**FGD Participants**		
Age in years	**Male**	**Female**		**Male**	**Female**	**Total**
20-25	3	3	6	3	3	6
26-30	4	4	8	4	4	8
31-35	2	3	5	3	2	5
36-40	3	4	7	5	6	11
41-45	2	3	5			
46-50	2		2			
51-55	1	1	2			
55 and above	1		1			
Total	**18**	**18**	**36**	**15**	**15**	**30**

As can be seen from table 1, all the FGD participants and 72 percent of the in depth interview key informants are between the age group of 20 and 40 years. Among the interview respondents who are under the age of 40 years, 54% are females.

Table 2: Educational background of Respondents

Educational Background	Sex		Total	
	Male	Female		
	No.	No.	No.	%
Reading and writing	3	5	8	12
1-4 grades	5	8	13	20
5-8 grades	11	9	20	30
9-12 grades	7	7	14	21
Certificate and college level	7	4	11	17
Total	**33**	**33**	**66**	**100**

Concerning educational background of the respondents, it is apparent in Table - 2 that 30 percent are from 5th to 8th grade levels while 21 percent of the respondents are between 9th and 12 grades. Most study participants (88 percent) have attended formal education.

Table 3: Marital Status of Respondents

Marital status	Sex		Total	
	Male	Female		
	No.	No.	No.	%
Single	11	8	19	29
Married	11	12	23	35
Divorced	5	4	9	14
Widow/widower	2	5	7	11
Separated	4	4	8	12
Total	**33**	**33**	**66**	100

Profile of Idirs Included in the Study

Out of the ten Idirs that are involved in the implementation of HCBC program, three Idirs were included in the study. The three Idirs that were included in the study were Idir number 112, 129 and 01. The three Idirs are established 1960's by the full concept and participation of Idir members. These Idirs have by-laws that are approved by members. The by laws include the rights and duties of members and strong penalties imposed on members incase of failing to fulfill duties. Membership in Idirs is generally open for any one who can pay the registration fee and the monthly contribution. The size of members of Idir varies depending on various factors such as the age of the Idir and the area of coverage.

Table 4: Members of Idirs Included In the Study

Name of Idirs	No. of Idir members	Date of establishment
No. 112	328	1962
No. 129	235	1964
No. 01	413	1961

Profile of Adama General Idirs Coalition

According to the document available in the Adama general Idirs office, initially 90 Idirs established general Idirs coalition in 1949. The main objective of Idirs coalition before 47 years was to help members to celebrate religious holidays together i.e. both Christian and Muslim holidays. The number of member Idirs increased over time, and currently the Idirs coalition has 158 members. The Idirs coalition revised its by-law four times following the socio-economic change and members need. The first by-law revision was made in 1979, the second amendment was made in 1982, the third revision was made in 1992, and the fourth

one was in 1997. Currently, the general Idirs coalition is revising its by-law to include HIV/AIDS prevention and control (support bed-ridden patients and orphans), elderly people and other vulnerable Idir members.

In the era of HIV/AIDS, Idirs were in a critical problem due to high number of death in the town. Idirs have been reached to the extent of running out of money to finance burial services and accomplishing the social expectations and their roles. Idir members were also tired of carrying out their duties that is burying the deceased due to the frequent death that affect the working time of members as such cases become not only so demanding but also stressful.

According to my informants from the general Idirs coalition, the number of people deceased and correspondingly the days of burial/funeral services increased with the advent of HIV/AIDS. It is obvious that the main reason of escalating incidences was HIV/AIDS. At the beginning, HIV was considered as the problem of promiscuous people. In addition to shortage of resources (time, money and materials) to support affected families, stigma and discrimination related to HIV/AIDS was major problem among the community. This situation put most Idirs in a precarious situation. Idirs started addressing the problem of HIV/AIDS initially in an unorganized way. Before two and half years the Idirs coalition has established partnership with FGAE Central branch office and Oromia Regional HAPCO to mitigate the spread of HIV/AIDS through the program of home and community based care (HCBC). Program partners have defined roles and responsibilities. The main actors, however, in delivering the services to beneficiaries are community based organizations/Idirs.

According to my informants from the General Idirs Coalition, general Idirs members are working in saving and credit scheme besides HCBC, supporting orphan and vulnerable children (such as school fee, school uniform, life skill training and food support), and

development activities in partnership with NGOs and local stakeholders as well as umbrella associations of PLWHAs.

What motivated Idirs to work on HIV/AIDS?

Idirs by-law has clearly stated about the objective of Idirs and membership. The main objective of Idirs was to support their members and families in time of mourning and bereavement. Idirs are community based organizations that are established by the full consent of members. The foundations are usually neighborhood; in some cases they are gathered on the basis of blood relations among relatives, among similar ethnic groups or sex-segregated in the case of women Idirs. As my informants from the coalition of general Idirs said,

> as a result of HIV/AIDS the number of death increased which, directly affected the survival of Idirs. Some Idirs dissolved while others failed to realize their objective due to the escalating mourn. The increasing number of death did not only pose financial problem on Idirs. In addition, Idir members were complaining of the recurring burial services that required them to give their time. Some members of Idirs started leaving the Idirs to escape these problems.

My informants from the Idirs HCBC committee explained that some Idirs decided not to perform burial services and not to give financial support if the person was suspected and died of HIV/AIDS. Idirs FGD participants mentioned the severity of the situation in the following words:

> the burial areas were busy and Idir members were totally exhausted whenever they hear Idirs announcement for members to participate in burial activities. This was the major challenge we (community members and Idirs) encountered before seven years. The situation was rather gloomy what we should do.

The HIV/AIDS problem is community problem, a pandemic that impeded the development endeavor of the country. As the FGD participants Idirs committee mentioned

they gradually started looking for a way out. They introduced HIV/AIDS prevention activities informally and independently with out binding rules. They further reported, overtime, they began to discuss and consult each other and agreed to participate in HIV/AIDS prevention and control activities through community based approach as a mechanism to mitigate the spread of the virus. According to the FGDs participants HCBC is a need based program that is designed to address the HIV/AIDS problem.

Selection of Partner CBOs/Idirs

The available document in the HCBC program office clearly indicted how the HCBC program has shown progress and develop into the current state. In their transformation efforts, General Idirs Coalition organized and conducted consultative meeting that involved 139 Idir leaders with the support of civil society and Oromia regional government HIV/AIDS prevention and control Office. The main purpose of the consultative meeting was to discuss on the socio-economic impact of HIV/AIDS and the role they can play to tackle the problem. In this consultative meeting Idirs agreed to participate in home and community based care to support bed ridden patients and affected families. In addition, the consultative forum identified criteria to select Idirs that could involve in the HCBC program. According to the HCBC program document, the criteria for the selection of Idirs were geographic location, membership size, willingness to participate in the HCBC, as well as those already initiated HIV/AIDS prevention and control by themselves. Accordingly, ten Idirs met these criteria, to involve in the HCBC program. Once the ten partner Idirs were identified, the next step was organizing meetings for the entire Idir members in their respective site to introduce HCBC program objective and thus get acceptance as well as approval of the community. All the ten Idirs members agreed on the idea and expressed commitment to give their support

for the HCBC program. In this series of panels, Idirs meeting participants selected five Idirs committee members to facilitate, coordinate and manage the HCBC program.

Building the Capacity of Idirs HCBC Committee Members

The FGD participant Idirs HCBC committee members mentioned that two days training on basic management skills was provided for Idirs HCBC committee members to build their coordination and management skill. Accordingly, Idirs committee members had conducted two experience sharing visit to Addis Ababa and Dessie to learn from other Idirs that had been implementing HCBC program.

According to interviews held with partner organizations, the management capacities of Idirs HCBC committees vary from Idirs to Idirs. Some Idirs need close support and inductive training while others have the capacity to accomplish the HCBC program effectively with minimum supervision. The main reasons mentioned for capacity limitations of some Idirs HCBC committee was frequent change of members and low academic background.

The coalition of Idirs leadership reported that,

> among the ten Idirs began the HCBC program, four terminated the HCBC program and substituted by other four Idirs. The main reasons for the HCBC program termination of the four Idirs have been associated with selection criteria of Idirs.

According to the available document in the HCBC program office, in the selection of Idirs to involve in HCBC program, Idirs located in the center of the town have had priority with the assumption that high number of service beneficiaries/patients is accessible in the area where a significant number of bars, night clubs and local alcoholic drinking houses are available. FGD participants from Idirs committee members mentioned that bed-ridden patients are found in the periphery of the town when Idir HCBC committees have started

identifying and registering beneficiaries. The Idirs HCBC committee mentioned that there was no reason for bed ridden patients to remain in the center of the town because they usually went to the outskirt to get low rate of house rent. General Idirs coalition chairperson mentioned that the Idirs coalition selected four Idirs from the periphery that are involved in the HCBC program.

Recruitment and Training of Care Givers (CG)

The available document in the HCBC program office indicted that each of the ten Idirs recruited trained and deployed ten caregivers each. (List of care givers by sex and Idirs attached- Annex 1). The criteria considered for selecting community caregivers was volunteerism to give care and support, living in the locality, education above grade $8^{th,}$, age between 18-45 years, gender (from both sexes), committed and dedicated, good communication skill, honest and disciplined (respect confidentiality and privacy of patients). The FGD participant from among care givers explained to the researcher that they become community home based care giver by their interest to cater such services for bed-ridden patients in order to improve the life of compatriots.

The HCBC program staff mentioned that among the 100 caregivers, 15 caregivers were with known sero-status disclosing that they are living with HIV/AIDS. One of these care givers participated in the in-depth interview said "she was beneficiary of the HCBC program at one time while she was a bed ridden patient." She further said, “there is no one who can understand the pain of bed-ridden patients more than me.” Indeed, her view is tangible as she has experience the situation both as patient and caregiver.

FGD participant caregivers mentioned that they are the second batch of the HCBC program that started providing care and support services in September 2006. The first batch has provided services for 18 months and substituted by the second group then after. They

further mentioned that they have attended three training courses i.e., basic home based care training for 21 days, training on nutrition for one week and three days training on community conversation. The community volunteers in the Focus Groups discussion acknowledged the quality and contents of the training and its strong impact on the HCBC program implementation capacity of caregivers. Among the FGD participant who is volunteer care giver said "care kits refilling process was smooth and commendable. However our concerns are insufficient working materials like heavy-duty gloves, uniform supplies and bicycles for transportation. We are here ten but only two have heavy duty gloves."

Beneficiaries unanimously agreed during the FGD that the knowledge of the caregivers has been adequate to face the challenge of providing care and building the skills of family members. Hence through such skill transfer process, home-based caregivers have sustainabily met patients day to day care needs. One interviewee among caregivers said about the training “my commitment is the result of these fruitful trainings”. He further explained "the training did not only build my knowledge and skill but also boost my moral and dedication to give care and support for bed ridden patients."

Program Staff Mix, Competencies and Retaining Staff

Interviewed nurse supervisor mentioned that the HCBC program has technical and support staff. The HCBC program of Adama have program coordinator, five nurse supervisors, agricultural Officer and support staff like cleaner, store keeper, guard, secretary and cashier. She further mentioned that staffs are responsible to follow, assist and supervise the activities of caregivers.

The ratio of staff especially nurse supervisors to voluntary care givers is 1:20 which is appropriate as mentioned by interviewees from staff and care givers themselves. As

mentioned by beneficiaries and caregivers in the FGD, the nurse supervisors have the appropriate skill and competencies to give care and support service and technical assistance. The major challenge of the program mentioned by the nurse supervisor, one of the key informants, was retaining staff. There was high personnel attrition due to various reasons. Four important staff positions i.e., program coordinator and three nurse supervisors were vacant when the researcher has been doing the data collection. The technical work of the program has been run by two program nurse supervisors. With two years period of the program, four HCBC Program Coordinators left the position. In addition, three agricultural officers left the post within six month. As mentioned by staff members in responding to interviews, the major reason cited for the high turnover of staff was getting education opportunity; better salary and work overload (burn out). According to the acting HCBC program coordinator, one of the activities that exhausted the HCBC program staff is the repeated vacancy announcement and the time taking recruitment process.

The high turn over of nurse supervisors also has a big impact on the HCBC program beneficiaries. One of my key informants said "I have already explained my health and other problems to the previous nurse; it is difficult to tell my secrets whenever new nurse supervisors assigned." The staff turn over therefore has inflicted confidentiality problem and suspicion on the side of patients.

HCBC program beneficiaries and Services provided

According to the guideline of the HCBC program “beneficiaries of the HCBC program are chronically ill-bed ridden patients residing in the area.” The program does not do any segregation whether the patient is bed-ridden by HIV/AIDS or either. The service is also accessible to beneficiaries that are members of the Idirs or not.

According to FGD participant from Idirs HCBC program committee and caregivers HCBC intervention provided a mix of care and support services that included psychosocial support, nursing care, environmental and personal hygiene, medical care, nutritional support, referral service, and terminal care. They also mentioned more other activities such as community mobilization, capacity building activities (trainings and experience sharing visits), documentation of best practices, networking, monitoring and supervision.

Focus group discussants among beneficiaries put need of patients in priority order: "nutritional support, housing, medical care, and psychosocial support." They also said "the program should include care for orphan, financial assistance and income generating activity."

Idirs HCBC Program Improved the Life of Beneficiaries

The major objective of the HCBC program was improving the quality of life of households and patients affected by HIV/AIDS. Ten out of the twelve-interview participant of beneficiaries and focus group discussants said "the HCBC services are tailored to our needs and have changed our life." As the researcher observed most patients participated in the interview (7 patients) did not have families that would offer them immediate care and support. Even those who have families (5 patients) interviewed said "our families did not give us proper care and support due to stigma and discrimination and fear of infection." Moreover, care givers mentioned that the HCBC program was helpful to reduce stigma and discrimination as a result of behavioral change communication that used culturally sensitive and tailored approaches such as coffee ceremony and community conversation. One patient pointed out that she has recovered and start moving as a result of nursing and medical care she obtained. She further said that "the supply of free antiretroviral therapy significantly improved my/our health." Data from the program indicted that during the nine months

period from July 2006 to march 2007, care and support services were provided to 309 (218 females and 91 males) patients, 267 persons obtained VCT service, 190 patients got free ART, 42 patients discharged from the service and 34 beneficiaries passed away. According to the nurse supervisor, the availability of free ART reduced AIDS mortality significantly.

In-depth interviews also show that PLWHA resume productive and social lives. A young man living with HIV continues to focus on his study at college; another young PLWHA cares for herself and working as voluntary care giver in the HCBC program. Six of the twelve interviewed patients expressed their need to involve in income generating activities.

The findings indicate that the HCBC program has achieved its objective. The effectiveness of the HCBC program is demonstrated by overall change in the situation of beneficiaries and reduced stigma and discrimination among the community that is verified by FGD and interview of the beneficiaries; care givers and partner organizations. However, the increasing number of bed-ridden patients particularly those seeking food support and the absence of income generating mechanism to engage recovering patients were the major challenges mentioned by all FGD and interview participants. The results of the research identified the extent to which resources availability has influenced the program. In most families, I observed the ability of the household members is very weak to contribute towards addressing patients needs.

According to my informant from the HCBC program staff, there is no guideline how to discharge patients from the service and the criteria to discharge patients from the program are not uniform. As a result, discharging a patient from the program particularly nutrition support was done depending upon the value judgment of the nurse supervisor and Idirs HCBC committee.

Networking and Referral service

The program has a referral network with Adama hospital, Oromia Region HIV/AIDS Bureau, FGAE's SRH Clinic, and other NGOs working in care and support. According to the interviewed chairperson of general Idirs and staff of HCBC program the network in general and the referral service in particular is not as strong as expected. Every NGO working in HIV/AIDS has made an effort to establish network but was not well orchestrated and planned.

According to program beneficiaries and care givers participated in the FGD, one of the major problems in the HCBC program of Idirs is referral service. Bed-ridden patients made repeated visit to health institutions for medical service including antiretroviral therapy. Patients are denied proper care and treatment in the hospital for various services. A typical caregiver said that "one of my patients passed three days in the corridor of Adama Hospital without proper medical services and treatment. In fact I understand there is shortage of staff in the hospital but the attention given to patients is generally very poor." Adama Hospital Medical staff mentioned in an interviewee session that shortage of health personnel that happened as a result of nurses attending skill up grading course was a problem to provide adequate and timely medical services to patients. FGD participant caregivers explained that "some heath personnel of the hospital did not recognize their voluntary work." They further explained the problem is more severe when the health personnel are new comers to the hospital. The referral linkage of the HCBC program with the hospital was not strong as expected. In addition, interviewees and focus group discussant among caregivers mentioned that they did not have identification card to show for health personnel and other support staff to get the required support. They have repeatedly asked the program coordinators (Idirs and FGAE Central branch Office) to get identification card but not yet materialized.

One of the requirements for patients to get free medical service in public health institutions was submitting paper from Kebelle administration that stated they are poor and did not afford for the services. Interviewed caregivers mentioned that most of the service beneficiaries were not residents of that kebelle and /or who are not registered in the kebelle. This was one of the big challenges to get the free paper. They also said "the free paper help to get service only for six months. If a client needs medical services for additional time he/she has to bring another paper from Kebelle administration." It is not difficult to imagine the burden on patients going ups and down to get the paper if it was not done by caregivers.

The other issue raised by patients in the group discussion was the absence of drugs and medial services prescribed for patients. Most of the time patients obtained drugs from the HCBC program and Adama Hospital as long as it is available. However, patients encountered a problem when the prescribed drug is not available in the hospital and HCBC program drug store. The other challenge-encountering patients were to get services like ultrasound and laboratory test which is only available in private hospitals. The HCBC program did not allocate money for this purpose. Therefore, it was big pitfalls for patients who are unable to pay for medical service and drugs, which are not available in the HCBC program.

Care givers during group discussion mentioned that bed-ridden patients need close medical support even though care givers and program nurse supervisors did whatever they can to give medical service in the patients home environment. On the other hand, there are situations where patients need to go to health institutions. The time may be during daytime or night. During day time they use ambulance, taxi or horse cart whatever available. The problem is serious when travel is inevitable during nighttime. In the group discussion, caregivers raised the problem they encountered to travel to the house of a patients during

nighttime and need the accompany of their family. During nighttime it is also a problem to get transportation service compared to the daytime. Focus group discussants among care givers said "the HCBC program covers transportation expense of patients."

Food Support: the Principal Question of Patients

Most beneficiaries of the HCBC program are poor, females who have no anyone on their side. The HCBC program and the caregivers are the one who are their families. The caregivers are everything to them. One of my informants told me:

> When I was seriously sick and bed-ridden patient there was no one around me except my four year old son. The HCBC caregivers come and do whatever they can to save my life. They are also successful to change my life. They gave me all the services what I want and recovered from my pain. They helped me to start ART. When I get out of bed they immediately terminate the food support. Now I do not have any thing to do. I have repeatedly asked the caregivers and Idir committee members to continue supporting me or find any other means to get any thing to eat. Other wise it is difficult for me to take the ART. If I know this was a criterion I better stay in my bed.
>
> *A 26 years old HIV positive woman, Kebelle 12*

This is the complaint of most HCBC program beneficiaries participated in the in-depth interview and group discussion. The Idir committee explained that the budget allocated for food support was in short of the demand. In each Idir, food support was allocated only for 30 patients i.e., for 300 bed-ridden patients in the ten Idirs. When a patient gets out of bed, the committees discharge her/him and leverage the support to other bed-ridden patient. This situation is one of the issues that have created complaint by patients. One of the key informants told me that “it is better for me to stay in bed if I know that they terminate the food support and have no any mechanism to engage us in income generating activities.”

During discussion, caregivers reported that whenever they went to the house of a patient the prime question is food. Nutrition support is the most needed support by patients and the inadequate support in the Idirs program. There is a big mismatch between the food support

supply and demand. One day I witnessed a caregiver, whom I interviewed, standing in front of a compound with beggars. He told me that he is waiting for the food he asked the owners of the house for his patients.

One beneficiary mentioned the need for food in a very convincing statement. She said,

> I am taking ART. When I was bed-ridden patient they provided me milk, sugar, edible oil and flour. You know the link between nutrition and medicine for infected person. Nutrition is essential for good health. I do not want the care giver to visit me unless he brings milk."

A Young woman living with HIV in Adama Keblle 12 stated that "I am still concerned about my health. I must drink and eat balanced meals. I must eat good and clean food."

I have observed a bed-ridden patient packed the milk and flour provided to her in a locker. I have asked her why she put it in the locker. The answer she gave me was very much depressing. She said "it is because other family members consumed my food and put me in hunger." This is a good indicator for the poor livelihood standard of the family. The family was poor and dependent that shared the food provided to the bed-ridden patient.

The HCBC program has recently integrated urban gardening to address the food shortage of beneficiaries. According to the HCBC program document, the urban gardening program has designed three strategies to supplement the food need of beneficiaries. The program planned to plant vegetables and fruits:

- In their home compound
- Using materials like container, and
- Using public areas like schools

The urban gardening has encountered challenges from the beginning. It was evident from the FGDs and interviews with patients and Idir committee members that most beneficiaries did not have their private house or compound. They are living in a house they rented from

individuals or kebelle administration, which is not totally suitable and safe for urban gardening. These houses have no compound and do not have available space for putting materials for planting vegetables. According to my informant from the HCBC staff, the HCBC program has started discussion with school administration to use school compound for vegetables plantation. The plants need water to grow and use for the intended purpose. However, covering the water bill for the vegetables is another issue that needs proper consideration if schools allowed the HCBC program to use the land for urban gardening. HCBC program beneficiaries raised the issue of gardening at a group discussion and said "gardening without a garden/plot is a difficult idea which cannot be practical". They also comment on the idea of using the school compound for gardening. They said "we do not have the capacity to travel long distance for gardening. It is also difficult to call it is a garden unless we look after now and then harvest it whenever we want." As a result of food shortage Care Givers, however, continue to experience many difficulties, and some feel unhappy being unable to help PLWHAs.

Housing Problem: the Big Concern of Patients

Idirs HCBC committee members in the FGD pointed out that most beneficiaries of the HCBC program are poor, come from other parts of the country for different reason including hiding themselves from relatives/any body who knows them, living alone without relative/family and have no regular income. Patients participating in the FGD mentioned that they were living and working in small business like local drinking houses, informal petty trade, daily labour and housemaids. Those who are living by renting houses from landlords have no the capacity to pay monthly house rent. Some Idirs are trying to cover house rents by mobilizing Idir members. The house they are living is not convenient for living. As one of the care giver explained "we are trying to clean the house to make it suitable to our

clients. However, the living area is not generally good and makes our effort worthless even though we go and clean 50 meters radius." One of the respondents told me the bad smell from the public toilet that is closer to her house disturbed her to sleep well. Another beneficiary mentioned that the house she is living is too cold and windy because the wall of the house is cracked.

Behavioral Change Communication

Community health education programs for HIV awareness and prevention, behavior change and stigma reduction, were organized for Idir members, influential peoples and religious leaders through coffee ceremony. According to PLWHA and caregivers participated in the group discussion, stigma and discrimination have been a serious problem at the beginning of the HCBC program. The caregivers further mentioned that neighbors have once considered them as people living with the virus even they were in good health condition caring their compatriots. During an in depth interview, one caregiver mentioned that she had received warning from her brother in-law to quit the voluntary service. She also added that the man informed her to quit the care and support service and will give her the money that she gets from the program. This indicates that the severity of stigma and discrimination in the area at the beginning.

The caregivers and patients themselves, however, mentioned the gradual positive attitudinal and behavioral change observed among the community as a result of information, education and communication programs. The coffee ceremony organized by voluntary caregivers has contributed for change of behavior among the community. Idirs HCBC committee during FGD mentioned that the community has understood stigmatization increasing vulnerability and the risk of HIV transmission and has started supporting patients. They also mentioned the increased awareness of the community and reduction of stigma and

discrimination by the following words. “At the beginning of the HCBC program period, it was care givers and Idirs committee members that identified bed-ridden patients for services. However, as a result of behavioral change communication and education and increased awareness, the one who provide information for care givers and referred patients for service are community members.”

One of my key informants have four children and has started taking ART before a year. Her three year-old son is also HIV positive. She has given birth before a month. According to my informant her husband did not have information about the HIV status of his wife and his son. She further said that “he leave home early in the morning and come home midnight. He is usually intoxicated with alcoholic drink and situations did not allow me to discuss the issue with him.” Notwithstanding the encouraging result in the reduction of stigma, this open discussion and disclosure problem indicates the need for intensive counseling service and interpersonal education to promote and strengthen behavioral change activities.

Local Resource Mobilization

Building the capacity of Idirs and local community was one of the strategies included in the HCBC program document to make the program sustainable and self-sufficient. Almost all study participants (interview and FGD) mentioned the commitment and devotion of Idir members to support the HCBC program and patients. According to my informant from the general idirs coalition, Idir members contributed one birr every month to support patients. They also participated in providing food and emotional support to encourage patients and affected families. The money contributed by Idir members was used for house rent, medical expense of patients, transportation and for other unexpected expenses. He further said that “community members also organized special occasions to patients and orphans and provide food support including meat to make them feel comfortable on holydays and religious

ceremonies." The local resource usually helped to cover urgent need of patients and affected family members. The FGD participant caregivers mentioned the point that has been repeatedly raised by the community. They said

> at one point in time the support of the community may be terminated and the community suggested the best solution is organizing PLWHAs in cooperatives to participate in income generating activities. They further explained the contribution of one birr is important to address the immediate need of patients but could not be a long term solution to patients' problems.

All the three focus group discussion participants underlined the need for strengthening and institutionalizing community resource mobilization to make patients self-supporting and self-sufficient.

Knowledge Transfer by Care Givers

One of the HCBC program strategies stated in the program document was building the capacity of family members to give care and support for patients in their home environment. FGD participant from care givers mentioned that the responsibility and burden of care givers in providing care and support for patients who are living with their families and alone were not the same. Care givers responsibility was relatively simple for patients living with family members and more of transferring their knowledge, providing supplies and counseling and making follow up of how family members care the patient. However, the Care Giver performed all the care activity for patients living alone. Patients that were participated in the FGD and in-depth interview acknowledged the capacity of caregivers in transferring skill to family members. According to FGD participant caregivers, there were family members they think it is the responsibility of volunteer caregivers to come every day to take care of their sick family member, even though they had the skill on how to take care of the patient.

They added that, currently, things have been changing and family members and the surrounding community have started to take care of patients.

Perception of Beneficiaries towards Idirs HCBC Program

Beneficiaries during the focus group discussion praised the HCBC services of Idirs as well as accomplishment and result of the HCBC program. Before the HCBC program, beneficiaries mentioned, patients were isolated and stigmatized by the community. No one was on their said. The Idirs HCBC program has shown a great change on the life of bed-ridden patients and on the attitude of the community towards HIV/AIDS. The program beneficiaries during group discussion mentioned that before the HCBC program no one wants to turn its face to us. Now we have learnt that we have friends, families, and compatriots. Patients in the FGD said "when Idir committees and care givers visited us (bed-ridden patients) other community members including family members started giving attention to us (patients).' They learned how HIV is transmitted and care to patients is one of the prevention and control mechanisms. Beneficiaries and caregivers as well as community members participated in the group discussion appreciated the HCBC program. However, there is a big question that they raised. "Most patients recovered and get out of bed, what is next? The HCBC program did not design income-generating mechanism. The food and material support usually terminate when a patient get out of bed." This is one of the big concerns of patients, care givers and Idirs committee members. This is, in fact, a question of sustainability as regards livelihood and future prospect of beneficiaries.

The issue of OVC Overlooked

As a result of HIV/AIDS, the number of orphan and vulnerable children increased dramatically. Patients participated in the group discussion and interview had mentioned their concern on the future of their children. The HCBC document did not have any program

component for orphan and vulnerable children. The caregivers participated in the FGD and interviewed program staff indicated that OVC is the other challenge of the program. When the families of the child died the burden falls on the shoulder of program staff and care givers. In the focus group discussion, care givers mentioned that most orphans did not have any one and considered us as close relatives. They know that we were the one who have been coming to their house and caring for their parent(s). A care giver explained the following situation that has shown the close relationship of care givers with patients and their families.

> A ten years old girl-child was absent from school due to the death of her mother. She was a student of grade four. After a week she went to school. The homeroom teacher instructed her to bring a relative. The only person she knows is the caregiver who has been taking care of her mama. She did not hesitate to inform the caregiver to go to school with her. He did what she has requested and helped her to continue her education.
>
> *A volunteer care Giver in Kidanemihret Idir (Idir # 112)*

It was observed that in most cases program staffs have been addressing the problem of orphan children by communicating institutions and individuals that could help these children. In some instances, program staff themselves have been trying to support orphans. The community where children were born and grew up also supported orphan children to retain them in the community they know. Care givers during FGD session mentioned that the HCBC program of Idirs did not design strong and formal system to care, support and maintain orphan children. During my first trip to Adama for data collection, I interviewed a patient who was living with her 12 years old son. After two weeks when I have been in Adama for the same purpose, I was informed that the woman I interviewed died and the boy has started leading life alone. The surrounding community has been supporting and assisting the AIDS orphan-boy. The care giver pointed out that “the support and protection of the

community was not structured and it is difficult to imagine how long the community assistance will be sustainable for the development of the child."

Supervision, Recording and Reporting

The HCBC program has established supervision, recording and reporting system. Interviewees among care givers, Idirs HCBC committee members and program staff mentioned and secondary sources ascertained that the program used timely review meetings, reporting and recording as well as field visit as a monitoring mechanism. Regular supervision have also been carried out by HCBC nurse supervisors, coordinator and Idirs committee. The program has weekly staff meeting led by the HCBC coordinator, weekly caregivers report submitted to the Nurse Supervisors and Idirs H&CBC Committees and regular feedback provided by Nurse Supervisors, monthly review meeting with caregivers facilitated by the Nurse supervisors, quarterly review meeting with Idir HCBC committees facilitated by project coordinator and Nurse Supervisors, and quarter review meeting with steering committee members that include program partners,

As learnt from the FGD, during review meetings caregivers submit performance report to Idirs HCBC committee and nurse supervisors. The HCBC program have well prepared and uncomplicated recording and reporting format. According to group discussion, care givers and interviewed staff, the monthly review meetings of care givers is a forum to exchange experience, identify bottlenecks and forward solutions. More over, available documents revealed that Idirs HCBC committee and nurse supervisors also organized community forums to disseminate information on the program performance and process and gather feedback from participants once in three months.

CHAPTER FIVE

DISCUSSION

Idirs are traditional community based organizations established to provide one time financial, psychological and funeral services to members in period of mourning. The impact and burden of HIV/AIDS on Idirs and the community compelled them to act in the prevention and control of the pandemic. Idirs in Adama town have started home and community based care programs to improve the life of people living with HIV/AIDS and affected families. Although Idirs in Adama have by-laws approved by members, they did not revise and include HIV/AIDS prevention and control activities in their byelaws. In their present functions, the community appreciated and supported Idirs HCBC activity.

The National Comprehensive Community-Based Care & Support guideline for PLWHA, OVC and affected families clearly stated the role of community-based organizations (HAPCO, 2006). The research finding disclosed that the role and responsibility of Adama Idirs were identifying eligible patients for care and support in collaboration with voluntary care givers, enhancing community mobilization to solicit their support, educating the community for the purpose of reducing stigma and discrimination, facilitating networking and recruiting, training and deploying voluntary HCBC providers as well as monitoring and evaluation of program activities. These functions of Idirs are consistent with the national home and community based care guideline.

Visible components of the Adama idirs HCBC program were nursing and medical care, personal and environmental hygiene, food and nutrition support, psychosocial and referral services. Voluntary care givers are the major actors in the provision of HCBC services. Caregivers have been found involved in the delivery of HCBC services by their freewill and interest. Of the total 100, 15 percent of the caregivers are HIV positive. Among these, HIV

positive care givers, some were patients and beneficiaries of the HCBC services. Selection of care givers based on their willingness and the involvement of PLWHAs contributed to program success in many ways. Beneficiaries and Idir HCBC committees that participated in the group discussion and interviews unanimously stated that caregivers are committed and knowledgeable in providing HCBC services. Basic training was provided to care givers for three weeks to build their knowledge and capacity. In addition, caregivers were trained in nutrition action and community conversation facilitation for five and three days, respectively. The various courses organized by the HCBC program were helpful to build the capacity of caregivers. According to FGD and interview participants, the trainings they obtained were sufficient to provide HCBC services. The commitment and devotion of care givers to support and assist patients have been highly appreciated by patients, Idirs HCBC committee members and the community in general.

Nurse supervisors monitor, guide and support the day-to-day activities of caregivers. The Nurses have the appropriate training and capacity to provide medical, psychosocial services to patients and also gave technical assistance to care givers. The ratio of nurse supervisors to care givers was 1:20, which is an optimum proportion to give technical assistant to care givers and provide services to patients.

The study revealed that the HCBC program has qualified and proper staff to run the program effectively and efficiently. Staff has acquired the required knowledge through training and experience sharing visits. The research identified high staff turnover as the major challenge of the HCBC program. Currently, four out of the six Adama HCBC program staff had resigned and the activity was run by only two technical staff. The Adama Idirs HCBC program has a serious challenge in retaining staff. For instance, four program coordinators took the supervisory position within two and half years of the program period.

Major reasons mentioned for high staff attrition, among others, were to pursue further education, better salary, stress and burn out syndromes. The research finding further identified that the HCBC program affected by the frequent staff recruitment and the subsequent long process it took to get qualified and experienced staff. Program beneficiaries have also complained change of service providing/ supervising nurses that caused by staff attrition. Whenever a nurse supervisor has been resigned a new nurse assigned to substitute the one that have had better experience. The new nurse usually stared her/his work with caregivers and patients. The patients are not comfortable to tell all their health history to the new comer. It usually took longer time until well rapport is established and close relationship and friendly atmosphere prevail between service providers and recipients. Therefore, high staff turnover have a dire impact on program performance and client comfort in relation to confidentiality is also threatened.

The HCBC program provided a variety of services to patients. Basically the objective of Idirs HCBC program was improving the life of chronically ill people living with the virus. However, the program provided services to all bed ridden patients for two reasons. The first reason is to avoid AIDS related stigma and discrimination. The underlying basis for this decision was if the care and support was provided only for AIDS patients, it would aggravate stigma by isolating them from other patients and community members. The other reason was that care and support should be given to all patients because they are also human beings that need community support. The provision of the service to all bed-ridden patients also helped to keep the confidentiality and privacy of patients. The research finding disclosed that most bed-ridden patients who have not learned their status have undergone HIV testing and know their sero-status after they started benefiting from the HCBC program. The contribution of caregivers in counseling bed-ridden patients to undergo VCT was paramount.

The national home and community based care guideline (HAPCO, 2006, P. 26) clearly stated home based care packages. These include: health care and support (medical package), food and nutrition, shelter and clothing, economic, psycho-social, spiritual, legal, and information, education and communication (IEC)/BCC. The Adama Idirs HCBC program components were in line with the needs of patients that include nursing/medical care, environmental and personal hygiene, psychosocial support, referral service, medical care, nutritional support, community mobilization and terminal care. In addition, the other activities of the HCBC program were caregivers kit refilling, capacity building activities (trainings and experience sharing visits), BCC, monitoring and supervision and documentation of best practices.

The Adama Idirs HCBC program has contributed a lot to improve the quality of life of patients. According to my informant from the HCBC program staff, 75 percent of bed-ridden patients could have gone out of bed. In addition to medical, psychosocial, personal care provided by Idirs HCBC program the contribution of anti-retroviral therapy in improving the life of patients was vital.

Despite the assistance of Idirs HCBC programs, beneficiaries described unmet needs. The HCBC program has limited capacity in providing nutrition for patients. The program has the limited capacity to provide food support for patients where as the number of patients that needs nutrition support is very large.

According to UNAIDS (2002),

> Given that the majority of people with HIV live in countries where many communities are under-nourished, nutrition must be addressed as an integral part of any strategy to ensure adequate treatment and care for people with HIV. Poorly nourished people get sick from HIV-related infections and other health problems sooner than if they had enough of the right food to eat. They also find it harder to fight infections and recover from health problems, thus further shortening their lives.

It is obvious that poverty is a common phenomenon and thus alleviating nutrition problem of people with HIV is challenging. In this situation, there was a big mismatch between the demand for nutrition support and food supply. For that reason, the HCBC program selected beneficiaries based on their health status and gave priority for bed-ridden patients. The problem worsens when the bed-ridden patients get out of the bed and at the same time the nutrition support terminated. Evidences from the FGDs have shown that, some recovered patients were sick and get in to bed when the food support terminated. As a result, some patients decided to stay bed not to lose the nutrition support.

The HCBC program has introduced urban gardening to address the nutrition need of patients. The urban gardening program has faced a challenge due to absence of plot for gardening. The program has considered three alternatives to solve plot shortage and grow vegetables. The first alternative was planting vegetables in the patient's house compound. However, the housing and living condition of most patients has been impoverished. Those who suffer from poor housing and living conditions did not have place for urban gardening. In order to overcome the problem putting containers to plant vegetable was found the second alternative designed by the program. The third option was using green areas of schools and other public places for vegetable planting. Using public plots for urban gardening needs the consent of authorities in these institutions and covering some other expenses like water, gardening and take care of plants. In addition, some patients did not have the gut to go far to cultivate the vegetables in these areas. The urban gardening activity needs reconsideration to make it fruitful.

Housing problem was also the major concern of patients. The Idirs HCBC program has tried to solve housing problem of patients by paying house rent and requesting kebelles to

get government rented houses, which are relatively cheap. Most patients visited by the researcher were living in a single room house unsuitable for living including absence of such essential facilities as toilet. A large proportion of patients did not have the capacity to pay house rent even for a single room. The statement of one patient is a good example to show how they have been coping the challenges of life. She said "I have consumed the money I deposited and saved in the bank and I sold all my property when I was seriously sick. I do not have any property for sale. I am here to see what will happen tomorrow." Most patients did not have income. This is an instance demonstrating the argument that the HIV/AIDS pandemic aggravates poverty and poverty also affects the HIV/AIDS prevention and control efforts by posing economic problem on patients. A study conducted in South Africa on the socio-economic impact of HIV/AIDS support this assertion. The study explained "the most frequent responses of households to financial crises seem to be borrowing, followed by the utilization of savings and the sale of assets, with a considerably larger proportion of affected households that had utilized these strategies also being affected by illness and/or death (Booysen, F & et al, 2002).

The HCBC program has linked the HIV prevention, care and support activities with other pertinent organizations through partnership and networking. Idirs HCBC program has strong partnership with FGAE Central Branch Office and Oromia Region HIV/AIDS prevention and Control Office. The linkage with government health institutions was also encouraging. According to the International Alliance on HIV/AIDS (2000, P. 6)) linking prevention and care enhances the impact, sustainability and credibility of the response to HIV/AIDS. It contributes to maximizing the use of resources and increases the potential to reach more people, including those who are most vulnerable to the impact of HIV. Therefore, the home and community based care and support program has identified the need for establishing

collaboration and linkage with pertinent partner institutions to bring about greater impact and wider client need coverage. Despite the medical services provided by voluntary care givers and nurse supervisors, patients made recurring visits to health institutions. The need for ART, TB, and other health service were among the major reasons that compel patients to make frequent visits to health institutions.

The HCBC program has planned and implemented various activities such as training for hospital staff, community sensitization workshops, joint review meeting and round table discussion to strengthen partnership with Adama hospital and health center. Although the linkage with these health institutions was encouraging, some times the partnership encountered problem where there was change of hospital staff. There was high staff turn over in Adama hospital because some pursue further education and some others were transferred to other work place. Patients usually faced challenges to get services when new hospital staff who has no information about the partnership program assigned in service provision.

Most patients are poor to pay for health services and requested medical services for free. The hospital demand patients to bring paper from Kebelle to get medical service free of charge. The hospital guideline also instructed patients to submit identification card (ID) to get TB medication. This situation has posed a problem on patients who come from out of their hometown and residing far from the kebelle they have registered as a resident. Idirs HCBC committee assisted patients to get paper from Kebelle for free medical service. For patients that need TB treatment, caregivers gave their ID card to Adama hospital to help patients to get directly observed treatment (DOTS). The problem of getting ID card was serious when more than one patient of a caregiver needs TB treatment.

Most of the time patients got drug from the HCBC program and Adama hospital. However, there are times where prescribed drugs were out of stock in the HCBC program and hospital drug stores. In addition, patients required to get ultrasound and specialized laboratory services from private hospitals which were not available in Adama hospital. The HCBC program did not allocate budget for such type of services and patients faced problems to pay for these services. Idirs tried to cover drug purchase and medical service expenses of patients from the monthly contribution of their members. However, the services provided by private hospitals and drugs from pharmacies are expensive that challenge the financial capacity of Idirs.

Strengthening the protection and care of OVC is one of the major program components stated in the national home and community based care guideline (2006). Adama Idirs HCBC program has no well thought-out program for orphan and vulnerable children. Evidences obtained through interviews have shown that orphan children living arrangement was made by volunteer caregivers, Idirs HCBC committee members and program staff. The program has no formally arranged and planned mechanism to address the problem of AIDS orphans. The issue of orphan and vulnerable children should not be ignored in a home based care program and has to be treated through direct intervention or/and formally established partnership with other child focused development agencies.

It is obvious that stigma and discrimination are key barriers to accessing care and support. The Adama Idirs HCBC program has behavioral change communication activity to mitigate stigma and discrimination. According to a book written on AIDS related stigma and discrimination “fear of stigma and discrimination keeps people from learning their HIV status, and if positive, from disclosing their status to others and accessing health services. Perceived and enacted stigma can place a huge psychological burden on an infected

individual and thereby contribute to a decline in health status (Mahendra, V. S., & et al, 2006). The HCBC program education strategies were community conversation and home-to-home visit. For this reason, caregivers are trained in community conversation facilitation techniques. The traditional coffee ceremony organized during the education activity made the session not only attractive but also culturally comfortable. The information and education activity targeted influential people, religious leaders, community members and local administration officials. The participants discussed on various HIV related issues and forward solutions to problems. During focus group discussion patients explained "before the HCBC program stigma, discrimination and isolation were major problems that led patients to self-stigmatization. Currently, AIDS related stigma and discrimination have been reduced and likewise community members have increased support and assistance to patients." The role of Idirs in mitigating stigma and discrimination is worth mentioning. Study findings indicated that a significant number of Idirs HCBC committee members reported that they have reached to the extent of holding discussion with individuals that made discrimination against patients. Patients developed confidence and positive attitude towards sero-status testing. Some patients have started educating the community about HIV/AIDS and become member of PLWHAs associations. The behavioral change communication activity of Idirs has demonstrated encouraging results in reducing stigma and discrimination.

Implication for Social Work Practice

At this juncture, it is essential to mention the role and contribution of social work practice to improve the life of the community in general and marginalized and vulnerable groups in particular. For the issue at hand, social work practice can play a spearheading role in reducing the spread and impact of HIV/AIDS by mobilizing and educating the community, participating in designing appropriate social policy and programs, strengthening social safety

net and social capital, and involving in community capacity building. As the National Association of social Workers (1999) stated, social work practice are aimed at enhancing human well-being and helping to 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. Social work practice mainly deals on social problems that affect individuals, families, and groups. As a matter of fact, HIV/AIDS is affecting individual and family well-being, peoples' livelihood, social institutions, and community assets. HIV/AIDS is a threat that increased peoples' morbidity and mortality and AIDS orphans. Hence, home and community based care programs undoubtedly requires the active involvement and prominent professional contribution of social workers.

CHAPTER 6
CONCLUSIONS AND RECOMMENDATIONS

Conclusions

Study findings revealed that home and community based care is an integral part of the HIV/AIDS prevention, care and support package in the continuum of care. Home and community based care has positive impact in improving the life of bed-ridden patients. The pandemic has been considered as health problem that could be addressed by health education and medical services provided by health institutions. However, through time, it is recognized that HIV/AIDS is a development problem that impede human advancement and that needs multi-sectoral response from the community, faith based organizations and other institutions in addition to government efforts. That is why the 1998 national HIV/AIDS policy clearly stipulated the need to involve all parties including community members at grassroots level to mitigate the spread of the pandemic.

Idirs have been established for the sole purpose of providing burial services and one time financial support to affected families. Idirs in Adama has started the HCBC program to address community problem and in turn to solve the impact of HIV/AIDS on Idirs survival. Therefore, the involvement of Idirs in HCBC activity has a significant contribution in improving the life of patients, community mobilization, care and support, and reducing stigma. Involvement of CBOs/Idirs in project implementation is crucial for the effectiveness of the project. The HCBC program has also started local resource mobilization from Idir members in the form of monthly contribution.

The main actors in the provision of HCBC services are trained voluntary caregivers that joined the program by their freewill and interest. The involvement of volunteer caregivers in the home-based care program has contributed a great stride for the

successful implementation of program objectives. The study finding revealed voluntary caregivers were committed, and compassionate for the purpose they stand. The capacity of caregivers in transferring skill to family care givers was also encouraging and that has created an opportunity to strengthen family and self-care. Sometimes volunteers used their own resources to cover the cost of caring for the sick person such as expending money for transport, food, and washing soap, and even for telephone call. In general, the work of voluntary care givers is acknowledged by the community and beneficiaries. It has also strengthened the notion of volunteerism, which was uncommon in the country.

Adama Idirs HCBC program has provided a package of services that include nursing care, psychosocial support, personal and environment hygiene, nutrition support, referral, palliative care and behavioral change communication. The HCBC program has improved the life of patients. Most patients recover and get out of bed as a result of the services provided by the Adama Idirs HCBC program. The program has established referral linkage with pertinent institutions including Adama Hospital and Health center for various services. Partnership and networking helped to provide comprehensive HCBC services.

The most frequently mentioned challenge of patients was not having sufficient resources to cover the costs of nutrition, house rent, and medical services. Community of the project area and beneficiaries appreciated the HCBC program and suggested the importance of organizing patients in cooperatives to involve them in IGA.

The HCBC program did not formally address the issue of orphan and vulnerable children. Program staff and care givers have tried to solve the problem of orphan children by discussing with institutions and individuals through placing children to institutional

care and adoption, respectively. The future of their children was a great concern for patients.

The HCBC program has a strong behavioral change communication strategy tailored to the specific needs of target groups. The strategy employed to disseminate HIV/AIDS focused messages were community conversation and interpersonal communication through home visit. As a result, AIDS related stigma reduced among the community and patients and community members have positive attitude towards the HCBC program.

The Idirs HCBC service has a follow up and monitoring system to give timely assistance for caregivers. Thus, review meeting, field visit, reporting and recording were the major strategies employed to supervise program performance and effectiveness. Monitoring and supervision activities were carried out at all levels of the program.

Recommendations

- Home and community based care program requires comprehensive referral linkage among implementing organizations. In the HCBC program there is an inherently weak referral system/links with the public health sector. Therefore, the HCBC program has to strengthen its referral chain with public health service rendering institutions.
- Despite the fact that Idirs HCBC program has provided essential care and support services to patients', the latter mentioned still more unmet needs. The program did not adequately address nutrition, housing and medical problem of patients due to insufficient resources and weak linkage with pertinent institutions. Therefore, the program has to strengthen its resource capacity including local resource and partnership to meet the need of patients.
- The HCBC program has no formally designed program component for placement of orphan and vulnerable children. The issue of AIDS orphans has to get proper attention in

HCBC programs. The program has to intervene in protecting and care of AIDS orphans by itself and/or through linkage with government and non-government organizations that have vast experience in child-oriented development activities.

- The human resource is a key challenge facing the HCBC program and requires immediate attention to minimize staff attrition. The HCBC program has to conduct study to identify staff retaining mechanism to motivate and reward staff. The HCBC program technical staffs are health professionals. The problem of PLWHAs is not only health problem that could be addressed by health professionals. In view of that, recruitment of staff from other professions such as social work and psychology is important to the successful implementation of HCBC programs and addressing the problem of patients.
- Many of the patients and households served by HCBC program are very poor. Linking HCBC program with income generation activities may alleviate some of the financial burdens they face. In addition, patients demand to involve in income generating activities. Therefore, HCBC program need to explore ways to assist households with income generation.
- Integration of reproductive health components especially family planning services to HIV/AIDS prevention activities including HCBC programs is essential. This has to be started with providing training to care givers (CGs). The caregivers have the opportunity to educate the community in general and program beneficiaries in particular about family planning methods and other related services. In some programs, community based RH volunteer agents distributed oral contraceptive pills and condoms. In this instance, this is not difficult for caregivers to distribute non-prescriptive contraceptive methods including condom, as this is the only double protection devise.

References

Booysen, F. le R., Bachmann, M., Van Rensburg, H.C.J., Engelbrecht, M., Steyn, F. & Meyer,

K. (2002). T*he Socio-Economic Impact of HIV/AIDS on Households in South Africa: Pilot*

Study in Welkom and Qwaqwa, Free State Province

Central Statistics Authority. (1999). *The 1994 Population and Housing Census of Ethiopia: Results at the Country Level,* Vol. 2, Analytical Report, June 1999, Addis Ababa

Ethiopia Central Statistics Authority and ORC Macro. (2005). *Ethiopian 2005 Demographic and Health Survey (DHS)*, Calverton, Maryland, USA.

Family Health International. (2004). *Module 4: Monitoring and Evaluating Community Home*

Based Care Program, Arlington, USA.

HIV/AIDS Prevention and Control Office (HAPCO), (2006). *Comprehensive Community-Based Care & Support Guideline for PLWHA, OVC and Affected Families*, Addis Ababa, Ethiopia

International HIV/AIDS Alliance Supporting Community Action on AIDS in Developing Countries, (2000). *Care, Involvement and Action: Mobilizing and supporting community responses to HIV/AIDS care and support in developing countries*, 2 Pentonville Road, London N1 9HF, United Kingdom

Mahendra, V. S., L. Gilborn, B. George, L. Samson, R. Mudoi, S. Jadav, I. Gupta, S. Bharat, and C. Daly., (2006). *Reducing AIDS-related stigma and discrimination in Indian hospitals, Horizons Final Report*. New Delhi, Population Council.

Nadeem Mohammad & Juliet Gikonyo, (2005). *Operational challenges Community Home Based Care (CHBC) for PLWHA in Multi-Country HIV/AIDS Programs (MAP) for Sub-*

Saharan Africa , Africa Region , Working Paper Series No. 88

Population Reference Bureau. (2005). *2005 World Population Data Sheet*. Washington DC, USA.

The Federal Democratic Republic of Ethiopia. (1989). *National HIV/AIDS Policy*, Addis Ababa, Ethiopia

The Federal Ministry of Health. (2003). *Health and Health Related Indicators 2002/3,* Addis Ababa, Ethiopia.

The Federal Ministry of Health (2004). *AIDS in Ethiopia 5th Edition;* Addis Ababa, Ethiopia.

The Federal Ministry of Health. (1998). Epidemiology and AIDS Department (2nd ed.) Addis Ababa.

The Federal Ministry of Health, (2002). *HIV/AIDS Home Care Handbook: Supporting Primary Care Givers in Ethiopia*. Ministry of Health, Addis Ababa

The National HIV/AIDS Prevention and Control Office and Federal Ministry of Health. (2004). *Ethiopian Strategic Plan for Intensifying Multi-sectoral HIV/AIDS Response*; Addis Ababa, Ethiopia.

The Federal Ministry of Health (2006). *AIDS in Ethiopia 6th Edition;* Addis Ababa, Ethiopia.

UNAIDS, (2002). *Improving access to care in developing countries: lessons from practice, research, resources and partnerships,* Geneva - Switzerland)

UNAIDS, (2004). *2004 Report on the global AIDS epidemic*. Geneva.

UNAIDS Update, (2005). *Report on the Global AIDS Epidemic*. Geneva.

UNAIDS, UNICEF, & USAID. (2004). *Children on the Brink: A Joint Report of New Orphan Estimates and a Framework for Action.*

UNAIDS, UNICEF, & USAID. (2004). *Epidemiological Fact Sheets on HIV/AIDS and sexually Transmitted Infections*. Ethiopia: 2004 up date.

Yemane Berhane, Tadesse Wuhib, Sanders E, Sileshi Lulseged, Shabbir Ismail, Zenebe Melaku, & Kloos H. (2006). *HIV/AIDS*, Addis Ababa, Ethiopia.

Tables

Table 1: Number of caregivers by Idirs and project beneficiaries by sex, May 2007.

S. No	Name of Idirs	Care givers by sex			Beneficiaries by sex		
		Male	Female	Total	Male	Female	Total
1	No. 112*	1	9	10	9	33	42
2	No. 40	1	7	8	10	17	27
3	No. 59	3	5	8	9	18	27
4	No. 75	4	5	9	8	21	29
5	No. 129*	6	7	13	17	59	76
6	No. 95	3	4	7	5	21	26
7	No. 17	2	7	9	11	10	21
8	No. 01*	3	5	8	11	29	40
9	No. 29	2	8	10	12	21	33
10	No. 105	2	7	9	10	14	24
Total		27	64	91	102	243	345

*Idirs included in the study
Source: Adama HCBC Program Office, 2007.

Table 2: Number of chronically ill patients reached by the HCBC service by age and sex from January - March 2006

S. No	Age Range	Male	Female	Total
1	≤14	3	6	9
2	15-24	8	23	31
3	25-34	26	62	88
4	35-44	27	44	71
5	45-54	22	17	39
6	55-64	12	28	40
7	≥ 65	6	21	27
		104	**201**	**305**

Source: Adama HCBC Program Office, 2007.

Appendix 1

Addis Ababa University

School of Graduate Studies

In-Depth Interview (IDI) Guide – 1

In-Depth Interview (IDI) guide to people living with HIV/AIDS and who are getting services from Idirs in Adama, Ethiopia, April 2007.

1. When do you learn your sero-status (HIV-status)?
2. How did you learn about your HIV-status?
3. As an HIV positive person, what kinds of services do you obtain? (go over the checklist)
   a. Education on HIV/AIDS? Health education for family members.
   b. Provision of condoms
   c. Emotional Support
   d. Spiritual Support
   h. Micro-credit/Income generating activities
   i. Assistance with funeral arrangements
   j. Blanket/Soap/Consumables
   k. Medical care for family members
   l. VCT for family members
   m. Nutritional support for children
   n. Referral? Agencies Name Purpose
   o. Who supplies you with these services?
4. Would you please put it your needs in priority order?
5. Do you think the services that you obtain are sufficient?
6. If not, what other major services do you expect?
7. Who else in your family gets the services?
8. When did you start getting the services provided by Idirs?
9. Have you ever been involved in teaching people about HIV/AIDS? If yes, how did you find peoples reaction?
10. Have you ever faced any stigma and discrimination in your living, working, recreational or any other areas?
11. Do you get any follow-up counselling? If yes, where?

12. Do you think the counselling you receive is useful? If yes, how? If no, why not?
13. Do you use antiretroviral drugs? If yes, how do you get them? If no, why not?
14. What are the major problems you encountered related to services?
15. Does majority of the PLWHA receive medical check-ups in the home OR do they travel to a health facility?
16. If PLWHA travel to a health facility for medical check-ups, does the Idirs program assist with a) Transport in a vehicle owned by the program b) Transport costs for public transport c) Personal accompaniment to and from the clinic
17. If PLWHA receive medical check-ups in the home, please explain the following, a) Who carries this out (nurse/doctor/other trained health care worker b) How often are the medical check-ups done.
18. Does the program a livelihood/income generation activity?
19. What is your comment on the services provided by volunteer care givers?
20. How do you get the services provided by nurse supervisors?
21. How often do they come and provide the services? Do you think this is enough?
22. Do you think the care and support services are tailored to the needs of beneficiaries? What else do you think is missed?
23. How do you evaluate the quality of services provided by care givers and nurse supervisors?
24. How do you see the respect for human rights, ethics, confidentiality, informed consent, privacy, and individual dignity in delivering services and discussion with care givers and nurse supervisors?
25. Do your family members give you home based care? What type of family relationship do you have?
26. Does any one from your family members trained/have orientation to give care?
27. How do you assess the relationship of volunteer care givers with family caregivers?
28. What is the role of Idirs leaders & members in the HIV/AIDS prevention & control? In providing care and support? In facilitating community mobilization and any other visible role that you can mention?
29. Do you think Idirs are giving the necessary attention to people infected with and affected by HIV/AIDS?

30. How do you explain the contribution Idirs? Are you happy with the service? Please explain in detail.
31. What do you propose to enhance the services?
32. Any other related points you want to mention?
33. Age
34. Sex
35. place of Birth _____ if not here(Adama) specify and when do you come_____
36. Marital Status
37. Number of Children; In school_____, out of school_____
38. Educational Background
39. Occupation: - Current _____, Previous _____
40. Is there any one in the family that involve in income generating activity?
41. Are you member of the Idirs?

Appendix 2

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In-Depth Interview (IDI) Guide – 2

In-Depth Interview (IDI) guide to Idirs HCBC committee members and Idir leaders in Adama, Ethiopia, April 2007.

1. When was the Idir established? Do you have legal registration to operate as CBOs?
2. How many members do you have at the beginning?_____ Now_____
3. Do you have by-law?
4. What was the main objective of the Idir?
5. Does it include providing care and support for people affected & infected? If not, have you modified the bye-law? If yes, what is new included?
6. What motivates you to involve in HIV/AIDS prevention and control? H&CBC?
7. Who decided to involve in H&CBC?
8. What is your source of income? Does the Idirs allocate budget for the program?
9. In the Idirs, who is responsible to coordinate the H&CBC project?
10. Do you have any training related to project management?
11. What are the major responsibilities of Idirs in HIV/AIDS prevention?
12. What are the services provided by Idirs to PLWHAs? OVC? And their families?
13. What are the expected numbers of patients to benefit from the interventions?
14. Does the intervention be able to meet expected demands?
15. What mechanism do you put in place to review intervention progress and contact with beneficiaries?
16. What have you done to involve communities in the implementation process? Involvement of beneficiaries?
17. How is the implementation of the program in relation to the need of beneficiaries?
18. What is the mechanism to collect feedback about the service?
19. What is you monitoring mechanism?
20. How do you evaluate the activities so far and the change in the life of PLWHAs?
21. What major problems do you encountered in implementing the HIV/AIDS project?

22. What are your partner organizations/groups to implement the project? What are the areas of partnership? How do you evaluate the benefits of partnership?
23. What are the gaps /problems in the partnership? If any.
24. Does the community/Idirs members actively participating in the HIV program? Have you any mechanism to involve the community in planning, implementation and monitoring? Give me detail information.
25. What contribution does the community have in the fight against AIDS?
26. How do you evaluate the contribution of Idirs in addressing the problem of PLWHAs? OVC? And their families?
27. Do you get any support from Governments and NGO's on your activities? If yes please describe.
28. What kind of role does your organization play to support the rights of people living with HIV/AIDS?
29. What are the major difficulties or problems faced by the Idirs? To the best of your knowledge, what challenges is the above C&HBC program facing
30. For the challenges listed in the above questions, what are the operational issues associated with each of the challenges and what are the possible solutions.
31. Do you participate in government activities related to HIV/AIDS? If yes please describe?
32. What can you tell us about the supply of materials, drug etc….?
33. What change do you observe in the life of PLWHAs/OVC as a result of the intervention?
34. Does the intervention benefit Idirs? What are these benefits of Idirs?
35. What are the major challenges you encountered and solution?
36. Any other related points you want to mention?

Appendix 3

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In-Depth Interview (IDI) Guide –3

In-Depth Interview (IDI) guide to Idirs HCBC program voluntary care givers in Adama, Ethiopia, April 2007.

1. Could you please tell me something about yourself?

   Your background? Your education? Your position/tasks in the organization?
2. Is this your full-time job? (paid/unpaid)
3. Could you please tell me about your organization?
4. What are the major responsibilities of your institution?
5. Population of the town/Adama
6. Number of health institutions: Hospital, HC, Health posts
7. Major health problems in the town.
8. What is the responsibility of your organization regarding the National HIV policy (Ethiopia)?
9. What roles does your office play to the right of people living with HIV/AIDS?
10. Would you explain to me the institutions (CBOs, NGOs etc) that are working in HIV/AIDS prevention & control?
11. Would you tell me the services provided by these institutions?
12. What is your work relationship with Idirs?
13. How do you perceive/evaluate the services provided by Idirs?
14. Do services provided by Idirs have contributed to the HIV/AIDS prevention and control?

    Improving the life of PLWHAs?
15. What is your relationship with the Idirs? Planning, implementation, reporting etc…
16. What are the major challenges or problems encountered in the implementation of HIV Policy in general and Home based care programs in particular?
17. What are the major challenges that encounter Idirs in project implementation?
18. How do you assess the services provided by Idirs? What is the understanding of your office about the services rendered by Idirs?

19. Do you have any information about the attitude /feeling of beneficiaries about the services provided by Idirs? If any explain to me.
20. What do think are the major limitations/gaps in the project? If any?
21. Is there a network of institutions that are working in HIV/AIDS? Explain.
22. Any other issues you want to explain.

Appendix 4

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In-Depth Interview (IDI) Guide – 4

In-Depth Interview (IDI) guide to for government (Health; HAPCO and Kebelle) Officials and NGOs representatives in Adama, Ethiopia, April 2007.

1. Age
2. Sex
3. Education
4. Occupation
5. How do you become caregiver? What motivates you to be a caregiver?
6. Who recruit you to be a caregiver? When?
7. What is your major responsibility?
8. How many months do you give services to beneficiaries?
9. Do you have any training to give the C&HBC service? For how many days?
10. What are the services you delivered to beneficiaries?
11. What is the feeling of beneficiaries towards the services rendered?
12. What support do you get from Idirs to carry out your responsibilities?
13. Are the services provided tailored to the needs of beneficiaries? Explain.
14. What is your work relationship with family members of beneficiaries?
15. How do you perceive/get the attitude of the community towards the services provided to beneficiaries?
16. Do beneficiaries consider the service as tailored to their needs?
17. What are the major complaints of beneficiaries? If any?
18. Please would you explain to me your work relationship with Idirs?
19. How many beneficiaries do you serve in total? Per month?
20. What are the criteria to give services to beneficiaries?
21. What is the basic procedure for home-based care visits?
22. What are the challenges you encountered in delivering services?
23. Would you please explain to me the planning, implementation & M&E process?

Appendix 5

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In-Depth Interview (IDI) Guide – 5

In-Depth Interview (IDI) guide to for H&CBC Nurse Supervisors in Adama, Ethiopia, April 2007.

1. Age
2. Sex
3. Education
4. Occupation /position
5. What is your major responsibility?
6. How many months do you give services to beneficiaries?
7. Do you have any training to give the C&HBC service? For how many days?
8. What are the services you delivered to beneficiaries?
9. What is the feeling of beneficiaries towards the services rendered?
10. What support do you get from Idirs to carry out your responsibilities?
11. Are the services provided tailored to the needs of beneficiaries? Explain.
12. What is your work relationship with family members of beneficiaries?
13. How do you perceive the attitude of the community towards the services provided to beneficiaries?
14. Do beneficiaries consider the service as tailored to their needs?
15. What are the major complaints of beneficiaries? If any?
16. Please would you explain to me your work relationship with Idirs? With care givers?
17. How many care givers do you supervise?
18. How many beneficiaries do you serve in total? Per month? Till now?
19. What are the criteria to give services to beneficiaries?
20. What is the basic procedure for home based care visits?
21. What are the challenges you encountered in delivering services?
22. Would you please explain to me the planning, implementation & M&E process?

Appendix 6

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Focus Group Discussion (FGD) Guide

FGD guide to Beneficiaries/patients Adama, Ethiopia, May 2007.

1. What kind of services do you obtain from the project run by Idirs?
2. Do you think the services you obtain are sufficient? If not, what is missed?
3. Do you get any follow-up counseling?
4. What is the approach Idirs utilized to provide service? How do you get the approach?
5. Do you think the services provided by Idirs are to the standard? Explain.
6. Do you think that the care and support services are tailored to the needs of beneficiaries? Explain.
7. What is your feeling, attitude and reaction towards the services provided by Idirs?
8. Does the project contribute to improve the life of beneficiaries and their families?
9. Have you seen attitude change on Idirs members and the community as a result of the project?
10. What are the challenges encountered in obtaining services?
11. Do you have any recommendation/suggestion to improve the service and approach?

Appendix 7

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Focus Group Discussion (FGD) Guide

FGD guide to Idir leaders/HCBC committees, Adama, Ethiopia, May 2007.

1. What was the main objective of the Idir?
2. Does it include providing care and support for people affected & infected? If not, have you modified the byelaw? If yes, what is new included?
3. What motivates you to involve in HIV/AIDS prevention and control? H&CBC? Who decided to involve in H&CBC?
4. What is your source of income? Does the Idirs allocate budget for the program?
5. What are the services provided by Idirs to PLWHAs? OVC? And their families?
6. Does the intervention be able to meet expected demands?
7. What have you done to involve communities in the implementation process? Involvement of beneficiaries?
8. What mechanism do you put in place to review intervention progress and contact with beneficiaries?
9. How do you evaluate the activities so far and the change in the life of PLWHAs?
10. What major problems do you encountered in implementing the HIV/AIDS project?
11. Does the community/Idirs members actively participating in the HIV program? do you have mechanism to involve the community in planning, implementation and monitoring?
12. What are the major difficulties or problems faced by the Idirs? To the best of your knowledge, what challenges is the above C&HBC program facing?
13. For the challenges listed in the above questions, what are the operational issues associated with each of the challenges and what are the possible solutions.
14. Does the intervention benefit Idirs? What are these benefits of Idirs? What are the major challenges you encountered and solution?

Thank You

Appendix 8

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Focus Group Discussion (FGD) Guide

FGD guide to Voluntary care givers, Adama, Ethiopia, May 2007.

1. How do you become care giver? What motivates you to be a care giver?
2. What is your major responsibility?
3. Do you have any training to give the C&HBC service? For how many days? Is it adequate?
4. What are the services you delivered to beneficiaries?
5. What support do you get from Idirs to carry out your responsibilities?
6. Are the services provided tailored to the needs of beneficiaries? Explain.
7. What is your work relationship with family members of beneficiaries?
8. Do beneficiaries consider the service as tailored to their needs?
9. What are the major complaints of beneficiaries? If any?
10. Please would you explain to me your work relationship with Idirs? With other care givers?
11. What are the challenges you encountered in delivering services?
12. Would you please explain to me the planning, implementation & M&E process?

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 acknowledged.

Name: Mohammed Yimer

Signature _____

Place: Addis Ababa University, Ethiopia

Date of submission: July 16, 2007

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

Name: Professor Sandhya Joshi (PhD)

Signature _____