



**ASSESSMENT OF HIV/AIDS CARE AND SUPPORT IN PEOPLE
LIVING WITH HIV/AIDS AT DEBRE MARKOS TOWN.**

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Assessment of HIV/AIDS care and support in people living with HIV/AIDS at Debre Markos town.

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Declaration

I hereby declare that the dissertation entitled ASSESSMENT OF HIV/AIDS CARE AND SUPPORT IN PEOPLE LIVING WITH HIV/AIDS AT DEBRE MARKOS TOWN submitted by me for the partial fulfillment of the MSW to Indira Gandhi National open University (IGNOU) new Delhi is my own original work and has not been submitted earlier to IGNOU or other institution for the fulfillment of the requirement for any other programme of study. I also declare that no chapter of this manuscript in whole or in part is lifted and incorporated in this report from any earlier work done by me or others.

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CERTIFICATE

This is to certify that Mr. Yigzaw Teshome Workie Student of MSW from Indira Gandhi National Open University, New Delhi was working under my supervision and guidance for his project work for the course MSWP-001 His Project Work entitled ASSESSMENT OF HIV/AIDS CARE AND SUPPORT IN PEOPLE LIVING WITH HIV/AIDS AT DEBRE MARKOS TOWN which he submitting is his genuine and original work.

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ACRONYMS AND ABBREVIATIONS

- AIDS** Acquired Immuno-Deficiency Syndrome
- ART** Anti Retroviral Treatment
- ARV** Anti Retro Viral
- CSA** Central Statistical Authority
- CSW** Commercial Sex Worker
- CVM** Comunita Volontari Mondo
- ECDC** European Centre for Disease Prevention and Control
- E.C** Ethiopian calendar
- ETB** Ethiopian Birr
- EU/EFTA** European Union/European Free Trade Association
- FDRE** Federal Democratic of Ethiopia
- FHI** Family Health International
- G.C** Gregorian Calendar
- HAPCO** HIV/AIDS Prevention and Control Office
- HAART** Highly Active Antiretroviral Therapy
- HBC** Home Based Care
- HCBC** Home and Community Based Care
- HIV** Human Immuno Deficiency Virus
- IGA** Income Generating Activity
- MOH** Ministry of Health
- NGO** Non Governmental Organization
- OI** Opportunistic Infection

PLWHA People Living With HIV/AIDS

PMTCT Prevention of Mother To Child Transmission

RRDA Ransom Relief and Development PLHIV Association

WHO World Health Organization

UNGASS United Nations General Assembly Special Session

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ABSTRACT

Introduction: People with HIV/AIDS experience a variety of health care problems, psychological traumas, stigma, and rejection by family members, friends and even medical personnel. If some amount of relief and normality can be given to them by ensuring proper care and support in the hospitals and in the community, as also protection of their right or privacy and other human right; suffering is reduced and improvement is seen in their living condition.

Objective: The main objective of this study to assess HIV/AIDS care and support of adult people living with HIV/AIDS in Debre Markos. **Methods:** The study employed qualitative research and descriptive research design to obtained information concerning the status of HIV/AIDS care and support of adult people living with HIV/AIDS. In-depth interview (for twenty PLWHA), and key informant interview (for two organization officials) were conducted. Non-probability, purposive sampling was carried out to select respondents. An interview administer pretested semi structured questionnaire was used. Determining analytical themes began with through reading of each transcribe interview in order to identify categories from the data. Then, cases prepared according to the analytical categories. Ethical clearance obtained from St. Marry University College, Addis Ababa research department. **Result:** Medical and Clinical care is one of the main care and support delivered to PLHIV. All of the participants had got medical care. But the economic support to PLHIV was minimal due to financial shortage of organizations. The most unmet need of PLHIV was house. Organizations involvement in care and support was limited. **Conclusion:** Among the four components of care and support medical and clinical care and psychosocial support particularly spiritual support were good. Even though there was economic support, but the support was not sufficient to solve PLHIV problems. In addition human right and legal support were not practically given to PLHIVs.

CHAPTER ONE

INTRODUCTION

1.1 Back ground

Globally 35.3 million people are living with HIV/AIDS of this 32.1 million are adults, 17.7 million women, and 3.3 million under fifteen children. Peoples newly infected with HIV are 2.3 million; of this 2 million are adults and 260,000 children under fifteen. Total deaths because of AIDS were 1.6 million among these 1.4 million adults and 210,000 children in 2012(WHO, 2012). Antiretroviral therapy reached 8 million people by the end of 2011 from 14.8 million people eligible for HIV treatment worldwide(UNAIDS, 2012).

The global burden of HIV is higher in low-income countries, where the majority of adults live with HIV (UNAIDS, 2010). Given the magnitude of the regional epidemic combined with the lack of adequate health infrastructure and human resources, it is necessary to develop community-based palliative strategies and end-of-life care models that adapt to local needs (UNAIDS,2010,Hubacher and McGinn,2008). PLWHAs face stigma, discrimination and other violations of their human rights. Protecting human rights and providing legal services for PLWHA and their families are critical components of HIV/AIDS prevention and care services (UNAIDS, 2010, WHO, 2010). Furthermore, the HIV/AIDS pandemic has caused extreme hardship in already impoverished populations. Globally, less than one in every three households that have a PLWHA is able to pay for basic health care (WHO, 2010).

In several countries, care and support services are provided by NGOs. For example, in Belarus, services provided by NGOs include palliative care, support groups, programme for children and families of people living with HIV, support programme for people who inject drugs and support

for people living with HIV in prisons. In Bulgaria, psychological and social support for people living with HIV is provided through NGOs in Sofia, Varna and Plovdiv. In Croatia, an NGO provides support services to people living with HIV in the same hospital where they are treated. In Serbia, support has been given to establishing a new organization of people living with HIV that is able to offer care and support programme. In Ukraine, care and support services are implemented exclusively by NGOs (ECDC, 2012).

Some countries expressed concern about over-reliance on NGOs for these services, including Italy, Moldova, Portugal and Ukraine. Few countries, however, expressed the desire to involve NGOs more in HIV responses (ECDC, 2012).

HIV epidemic is mostly widespread in Sub-Saharan African countries 25 million (70.8%). Adult prevalence 4.7% with adults and children newly infected with HIV 1.6 million. The part of the world most impacted by HIV i.e. 1.2 million death due to AIDS in 2012. In Sub Sahara Africa the gap between people who can access treatment and people in need is still very large, nearly 6.2 million people receiving HIV treatment among 11 million people eligible for HIV treatment (UNAIDS, 2012).

Ethiopia is one of the countries with large number of people living with HIV. It is estimated that 789,900 people are with HIV (607,700 adults and 182,200 children aged 0-14 years) and 952,700 AIDS orphans (EDHS, 2011). In Ethiopia 1.5 percent of adults are infected with HIV. Among women age 15-49 HIV prevalence is 1.9 percent, and men age 15-49 and 15-59, HIV prevalence is 1.0 percent. HIV positive among women and men age 15-49 in *Amhara* region is 2.2%.

With the spread of the infection across the country and the sharp rise in the number of persons living with HIV/AIDS in the society, Care and Support including home-based care has been made an integral component in AIDS Control Programme. There is a moral and humanitarian obligation to provide appropriate care and support to persons living with HIV/AIDS. People with HIV/AIDS experience a variety of health care problems, psychological traumas, stigma, and rejection by family members, friends and even medical personnel. If some amount of relief and normality given to them by ensuring proper care and support in the hospitals and in the community, suffering reduced and improvement seen in their quality of life (IFRC,2009).

1.2. Statement of the problem

Most countries in Europe and Central Asia, particularly in the EU/EEA, have a strong focus on delivering treatment, care and support for people living with HIV, in particular, providing antiretroviral therapy (ART) to those who need it. The number of people receiving antiretroviral therapy in countries across the region has increased. The rate of increase has been particularly high in non- EU/EFTA countries. However, rates of late diagnosis are high in EU/EFTA countries. Approximately half of all those diagnosed with HIV already require ART at the time of diagnosis. EU/EFTA countries face a number of challenges in providing HIV treatment care and support to those who need it. Challenges identified include: financing the increasing number of people requiring ART, expanding ART to all those with a CD4 count <350, limited availability of HIV specialists, interruptions in antiretroviral drug supplies, difficulties in decentralizing ART provision and support services in some countries, ensuring professional quality of services, improving retention/adherence of those on ART, emerging drug resistance, need for advanced clinical services in some countries (ECDC, 2012).

A wide range of population was identified by ECDC as facing difficulties in accessing HIV care and support. In many cases, countries reported efforts to provide specific programme for this population. This population included key population at increased risk of HIV infection like migrants, people who inject drugs, sex workers, and gay, those in places of detention, People lacking health insurance, those who are socially marginalized, and Children in Europe (ECDC, 2012).

HIV/AIDS demands high expenditure to provide PLWHA with medical and nutritional support. Moreover, the probable serious health complications that HIV will likely cause as well as stigma

and discrimination. In the working environment may also hinder opportunity of engaging in income generating activities or diminish the capacity of a person to remain employed. Consequently, as women are the most economically marginalized group of the society, coping with such financial stress and loss of employment poses a debilitating situation for their attempt for survival.

In addition to expanding coverage to those currently not accessing services, developing countries such as Ghana now face the challenge of sustaining and managing existing programme. Ensuring the quality of services delivered will be critical as ART for AIDS requires high-quality programme to maintain optimal clinical status to PLWHAs(Ampofo, 2009). Greater attention must also be devoted to those who are harder to reach, including rural populations, who make up a substantial proportion of those currently with low access to HIV services. Groups at high risk of HIV infection, such as sex workers, gays, long distance truck drivers and migrants should also be a major focus of attention. The current pace of scaling up is inadequate.

In Ethiopia home based care was adapted as a strategy in 2002 to support PLWHA however, the quality and duration of care are uneven largely due to stigma and lack of resources and some PLWHA are even abandoned(Berhane et al. 2006, MOH,2002).

Organizations, external donors and concerned governmental bodies providing care and support services have to maximize their financial, human and material supports to a level that best fits the needs of PLWHAs. It is up to all concerned organizations to utilize the current prospects and opportunities available to maximize their activities and bring tangible changes on the life of PLWHAs (MOH, 2002).

HIV/AIDS prevention and control programme especially care and support mostly depends on foreign donation. However, due to financial and economic crisis in the western developed nations results to a shortage of fund for developing countries to implement the programme.

As far as the researcher knew there are little studies that have described the care and support of PLWHA, in order to sustain HIV/AIDS care and support, study should be conducted. Thus all above mentioned problems require an urgent response from both governmental and other stakeholders in HIV/AIDS care and support. Therefore the rational to assess HIV/AIDS care and support is to explore/describe the current situation of adult HIV/AIDS care and support, identify the problem facing, and to fill the information gaps in the study area. It will have alsovaluable contribution toindicate priority-seeking areas for social work intervention besides adding someknowledge to the discipline and indicate alternative ways for addressing adult care and support of PLWHA.

1.3 Significance of the study

The psychological, social, legal and clinical care and support plays a significant role in improving the living condition of individuals and families affected by HIV and AIDS. Therefore, the finding of this study focused on the four components of care and support and will serve as baseline information as well as encourage other researchers who are interested to conduct further investigation on the problem under investigation. It may use as reference material for researchers, experts or policy makers for intervention on HIV/AIDS Care and Support. It will influence government, NGO, CBOs and other stakeholders in addressing adultHIV/AIDS Care and Support in Ethiopia in general and in Debre Markostown in particular.

1.4 Scope of the Study

This study was limited to adult HIV/AIDS care and support in Debre Markos town, PLWHAs who are vulnerable to various socio-economic and psychological problems. It focuses on the assessment of adult HIV/AIDS care and support.

CHAPTER TWO

LITERATURE REVIEW

2.1 General overview of HIV/AIDS Care and Support

More than two decades into the AIDS pandemic, substantial gains have been made in understanding how HIV is transmitted and its effects, including physiological, psychological and socioeconomic ones. At the community level, the epidemic has left populations devastated, resulting in an increased burden on countries to support people who are ill, as well as those who are left behind. Countries face different epidemic dynamics, and governments must respond in a timely and efficient manner to mitigate the impact of this disease. For countries in which the infection is widespread among the general population, prevention efforts must continue while care and support are provided. These efforts should focus not only on the people infected but also on the families and children affected by AIDS. Only through increased efforts to mitigate the impact of the epidemic can people living with HIV/AIDS hope to continue leading productive lives for as long as possible and devastated communities may continue to function. By providing services for people living with HIV/AIDS, governments can hope to minimize the negative national and individual effects of HIV/AIDS (WHO, 2004).

Research in several countries across the globe suggests that psychological support, healthcare support, spiritual support, alimentary supplementation and financial support are the core needs of PLWHA. There is now a general recognition that comprehensive care across the continuum should be provided to PLWHA through all the stages of infection, with a crucial role for community-home based care activities. The care and support needs of PLWHA and their families can be categorized in four interrelated domains: medical needs, psychological needs,

socioeconomic needs, and human rights and legal needs. Major challenges remain in scaling-up Antiretroviral Therapy (ART), income generation and meeting nutritional needs of the rapidly increasing number of affected families and orphans (Tadesse et al., 2011).

People living with and households affected by HIV/AIDS require a wide range of services, including psychological, social, legal and clinical ones. Care and support programme must therefore be developed to respond to these needs and demands. Complicating the situation, these needs reflect an environment in both industrialized and resource-constrained settings in which stigma; discrimination, fear, neglect and impoverishment surround HIV/AIDS to various degrees in the community, workplaces and health care settings.

To address these needs, HIV/AIDS care and support programme should have the objectives of: ensuring equitable access to diagnosis, health care, pharmaceuticals and comprehensive supportive services; reducing morbidity and mortality from HIV/AIDS and related complications; promoting opportunities for preventing HIV transmission within the delivery of care and support services; and improving the quality of life of both adults and children living with HIV/AIDS and their families (WHO, 2004).

2.2 Components of HIV/AIDS care and support

Providing care to people living with HIV/AIDS and to their families requires a broad range of services that include not only clinical care focusing on diagnosis and treatment but also supportive and complementary services to ensure that adequate nutrition, psychological, social and daily living support are available. Efforts to prevent HIV transmission also need to be strengthened whenever opportunities arise.

Comprehensive HIV/AIDS care must include clinical care for everyone, psychological support, socioeconomic support, involvement of people living with HIV/AIDS and their families and respect for human rights and legal needs (WHO, 2004).

Clinical care for everyone: - ***Everyone*** should receive clinical care regardless of gender and age. Services include counseling and testing for diagnostic purposes (including dedicated programme of voluntary counseling and testing); prophylaxis of opportunistic infections; management of HIV/AIDS-related illnesses; control of tuberculosis and management of sexually transmitted infections; management of HIV disease with antiretroviral combination therapy; palliative care; access to drugs related to HIV/AIDS, including drugs for opportunistic infections, cancer related to HIV/AIDS and antiretroviral drugs; interventions to reduce the mother-to-child transmission of HIV; support systems such as functioning laboratories and drug management systems; nutritional support; health education measures; adequate universal precautions in clinical settings; and postexposure prophylaxis (WHO, 2004).

Psychological support: - Psychological support includes initial and follow-up counseling services to meet the emotional and spiritual needs of people living with HIV/AIDS and their families and to assist in disclosure, including psychosocial support through support groups (post-test clubs) and other peer, volunteer or outreach approaches within communities.

Socioeconomic support: - Material and social support is needed within communities to ensure that nutritional and daily living needs are met. Various options include microcredit schemes; housing; food support; helping hands in the household; health insurance schemes that include

HIV/AIDS care and treatment; and planning and support for orphans and vulnerable children in households and communities.

Involvement of people living with HIV/AIDS and their families:-People need to be involved in the planning and delivery of comprehensive care to ensure that HIV/AIDS care, treatment and support programme intended for them address their needs, reinforce adherence, prevention and care, promote health-seeking behavior and respect their human rights.

Respect for human rights and legal needs:-Services are needed that address stigma and discrimination in health facilities, in communities and in the workplace and promote equal access to care. This should also include succession planning and protection of property (WHO, 2004).

In a cohort study in the southern United States, greater family support at baseline was found to be predictive of positive changes in physical health and social functioning among PLWHA who were on highly active antiretroviral therapy (HAART) (Jia et al.,2005). Another study has shown that family support is predictive of reduced risk behaviors among HIV-positive gay men (Kimberly and Serovich, 1999).

Study done in California, Los Angeles revealed that, adolescents who had more social support providers reported significantly lower levels of depression and fewer conduct problems; adolescents who had more negative influence from role models reported more behavior problems. Reductions in depression, multiple problem behaviors, and conduct problems were significantly associated with better social support. Psychosocial, legal and human right services are widely neglected or are not given due attention by almost all caregivers as part of the

standard of care and support. Modest achievements were observed in the provision of medical and nursing care services including: palliative care, bed-based nutritional support, family planning, preventive therapy and others (ECDC, 2012).

China is a family-oriented society. Given the potential risk of HIV/AIDS pandemic in China and the important role families play in the life of PLWHA, the need to study families living with HIV is clearly presented. A good understanding of the role of families in the lives of PLHA can better inform the design of an HIV-related intervention, and also make existing programme become more accessible to the targeted population (Li et al.2010).In addition to economic hardship, families living with HIV usually face tremendous social pressure and discrimination. In Nigeria, when one member of the family becomes HIV-positive, the whole family will be called an “AIDS family” by other villagers (Alubo O., Zwandor, A., Jolayemi, T.,Omudu, E. , 2002). Everyone in the family experiences shame when being treated discriminatorily by members in their social network. In Thailand, if the status of a PLHA is disclosed, the whole family fears losing face (Songwathana, P. and Mandorson, L., 2001). This is especially true in a family-oriented society like China.

When facing societal discrimination and other hardships related to HIV/AIDS, a strong and supportive family is one of the first lines of defense .Study suggested that when parents are too sick to take care of children themselves, the grandparents usually become the primary caregiver for their grandchildren (Bor, R. ,Miller,R. , Goldman, E. , 1993). In Thailand, as well as many other countries, families affected by HIV/AIDS provide psychological and economic support to their infected family members (Manopaibonet al., 1998). On the other hand, in a study conducted in Mexico,results argued that the majority of family members displayed negative responses to a

family member's HIV diagnosis. In this case, HIV became a catalyst of pre-existing family conflicts (Castro et al., 1998).

In the five African countries that they included in their study (Botswana, Ethiopia, Tanzania, Uganda, and Zimbabwe) Sepulveda and colleagues estimated that each year, at least one in 200 people needed palliative care at the terminal stages of HIV/AIDS or cancer (Sepulveda et al., 2003).

Studies have shown that disclosure of HIV-positive serostatus can result in greater social support, which in turn has positive effects on psychological well-being (Ostrow et al., 1989). Another study conducted in South Africa result revealed that social support, especially family support, was significantly related to disclosure of HIV status (Sethosa E., and Peltzer K., 2005).

According to the study conducted in Ethiopia care should include psychological, social, and economic support as well as broad based medical care incorporating nutritional guidance, prevention and treatment of opportunistic infections and palliative care. In Ethiopia, local health facilities emphasized medical and nursing care; however, this was not according to the continuum of care and was entirely dependent on external financial support. Given the limited number of associations providing this services in the area, current and new methods of communication should be strengthened and implemented to prevent overlap and make service provision of better quality and more efficient. Services should also include home-based care and support, which was reported as preferable by PLWHA who participated in this study. Previous research conducted in Jimma, Ethiopia showed that home is an ideal place for medical, social and psychosocial care and support. These findings are supported by research in East Africa that

explored quality of care and unmet needs of people requiring palliative care (Abebe T. and Aase K., 2007).

The home-based care program plays a significant role in improving the quality of life of individuals and families affected by HIV and AIDS. In August 2009, FHI conducted an outcome study to assess the results and impact of the HCBC program. Study findings show outcomes of the HCBC program in five categories, including reduction in stigma and discrimination of PLHIV and OVC, increased acceptance and use of voluntary testing and counseling, improved PLHIV health and well-being, improved household economic conditions of PLHIV, OVC, and other beneficiaries, and increased community support by idirs. The findings clearly show that the HCBC program has resulted in improved health status of clients and reduction of self-stigmatization, and PLHIV now communicate more openly with their families and neighbors. The HCBC program has increased awareness of and facilitated access to treatment. Results of the FHI study show that the death rate dropped by 9.3% in four years. (Helmut K., Tadesse W., Damen H., and Bernt L., 2011).

The study assessed care and support activities provided to PLWHAs by various institutions in Arba Minch, Ethiopia. The study showed that 141(62.4%) participants who received care and support services were females between 26–30 years of age. The findings underscore that almost all of the care and support activities available are not adequate and not well organized. This is evidenced by the proportion of PLWHA who received care and support as well as by the various components of the care and support activities.

PLWHA have diverse and complex needs in terms of access and provision of care and support services. From the sample of 226 (100%) participants, only a quarter obtained some type of

material support. This reflects the limited access of care and support services that is prevalent, and points out to the urgent need to scale-up these services in this region. Scaling-up services could potentially have a significant impact in the social skills of PLWHA and could further impact productivity within their communities. Furthermore, technical support and material support should be increased to adequately provide services and to identify barriers and challenges for service provision and to develop plans to address them (Tadesse et al., 2011).

Barriers to accessing services in all women's focus groups were: lack of adequate personal finances to get nutritious food, transportation, a phone, adequate housing, and quality of life enhancements, such as visiting family. For women with children, access to childcare for appointments was a barrier. Red tape and bureaucratic requirements (e.g. notes from doctors) was another huge barrier for clients (Jane A., 2002).

From the comprehensive care and support activities that needs to be provided to PLWHAs, the GOs were mainly involved in the provision of psychosocial, medical and nursing care; while the NGOs were mainly involved in the provision of socio-economic and psychosocial support (Tadesse et al., 2011)

The study found that among the various supports that was given to PLWHA, only 58 (25.7%) of the responding PLWHA had obtained material support. Another component of socioeconomic support assessed was related to the involvement of PLWHA on different income generating activities. It was found that 50 (22.1%) respondents were supported to be involved in such activities. Out of the total number of respondents, 144 (63.7%) had obtained food support at least once in the past 12 months (Tadesse et al., 2011).

Out of the 226 (100%) respondents, 186 (82.3%) got access to services with the assistance of an NGO. Family planning was also given to 88 (38.9%). Care provided was ethically appropriate for 19 (44%) respondents. In addition, other medical and nursing care services that the study participants obtained included bed nutritional support for 40 (95%) and 160 (70.8%) participants were on ART medication (Tadesse et al., 2011).

Among the various activities that need to be undertaken to support human rights of PLWHA, they identified assistance to cope with stigma and discrimination, co-planning to help them improve their quality of life and attempting to secure equal opportunities as activities that were being provided in the area. Among the 226 (100%) participants, other than the attempts made to alleviate stigma and discrimination to 144 (63.7%) participants, almost all of the above three activities were provided to less than half of the PLWHA. Only 72 (31.3%) of them were involved in developmental activities and other type of activities, while 76 (33.3%) of them were involved in planning for improvement of quality of life, and the remaining 106 (46.9%) were helped to get equal access to services at the work place or at social facilities (Tadesse et al., 2011)

Participants reported almost no psychosocial support. Only 10 (4.4%) participants had their cases followed-up and 128 (56.6%) participants said they had obtained counseling services. More than half of the sample, 118 (52.2%), reported spiritual support from religious groups, while the remaining 104 (46%) were given community moral support as part of psychosocial support. The major drawback of care and support activity is the lack of evident referral and linkage system between different organizations. Four of the organizations providing care services didn't have any referral forms for inter-organizational communication, except for the existence of referral

tools which were non-specific and were mainly used for intra-organizational communication (Tadesse et al., 2011).

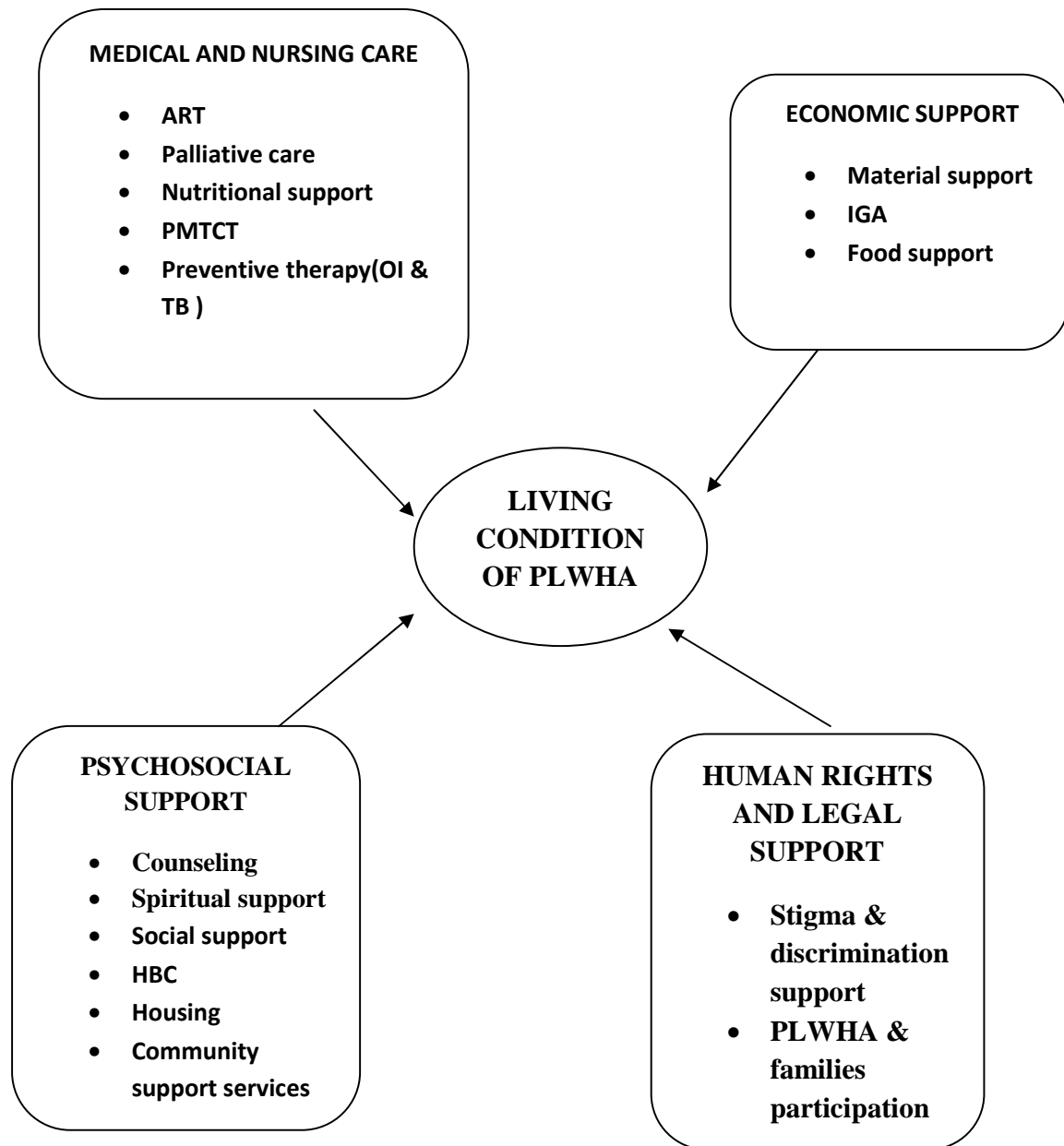


Figure 1: conceptual frame work ofassessment of HIV/AIDS care and support on people living with HIV/AIDS at Debre Markos town.

CHAPTER THREE

OBJECTIVE

3.1 General objective

- To assess HIV/AIDS care and support in people living with HIV/AIDS.

3.2 Specific Objective

- To describe adult HIV/AIDS care and support in Debre Markos town.
- To identify the problems of adult HIV/AIDS care and support.
- To identify the needs of people living with HIV/AIDS.

In relation to the objectives the following major research questions outlined

1. What kind of HIV/AIDS care and support provided to PLWHA?
2. What are the problems of HIV/AIDS care and support?
3. What are the needs of people living with HIV and AIDS in the town?
4. What is the involvement of organizations in addressing HIV/AIDS care and support in the town?

CHAPTER FOUR

METHODS AND MATERIALS

4.1 Study area

The study was conducted in Debre Markos, Amhara Regional State. Debre Markos town was found in 1853. The town is located at 10° 19' North latitude and 37° 40' East longitude. It is found in Amhara National Regional State East Gojjam Zone Administration. Debre Markos is the capital town of East Gojjam Administrative zone. The town is situated on the interregional route from Addis Ababa to Bahir Dar at a distance of 295 k.m. from Addis Ababa to the North West and 265 k.m. from Bahir Dar to the North East. Based on the 2007 census population projection of Amhara Region Finance, Economy and Development Bureau, the town has a total of 83,857 (Male= 40,147 and Females=43,710) population in 2014. Regarding the health institutions the town has one referral hospital, four health centers, seven health posts and different private and nongovernmental clinics. ART service is delivered only in Debre Markos Referral Hospital and in Debre Markos Health Center.

Debre Markos Referral Hospital was established in 1965 which started providing ART care service in 2005. The total numbers of clients ever enrolled are 8,725 PLWHA. And 5139 PLWHA were currently on follow up.

In addition, Debre Markos Health Center established in 1969 delivering ART service to clients in 2008. Six hundred and sixty six people living with HIV/AIDS were followed their ART in the center.

4.2 Study Design

The study has employed descriptive type of research design. Because descriptive research designs assisted the researcher to find out facts and describe HIV/AIDS care and support in PLWHAs in Debre Markos town. Therefore, it was significant for the researcher to employ this type of research design to conduct the study effectively.

4.3 Study population

The target population of the study were residents of Debre Markos town adult PLWHAs; those who had follow up at Debre Markos Referral Hospital and Debre Markos Health Center ARV treatment and care center.

4.4 Sampling method

Because of the objective and the nature of the problem under study, and the difficulty of accessing PLHIV through the survey method, qualitative research approach was used. The researcher also used purposive sampling techniques from the non-probability sampling methods to select respondents. The method helped for the researcher to obtain more reliable information. This sampling technique employed deliberately since the researcher has considered as a good means of obtaining information that made the sample more representative for the entire population.

4.4.1 Eligibility criteria

Inclusion criteria

PLWHAs who were the age of between fifteen to forty nine years and have ART visit in Debre Markos Referral Hospital and Debre Markos health center during the study period June 2-13/2014 and those who can communicate well or not seriously ill were included in the study.

4.5 Data Collection procedure

An in depth interview semi structured questionnaire and, key informant interviews conducted with HIV care providers organization heads. First it was prepared in English and then translated into Amharic and finally to the English version to ensure its consistency.

The in-depth interview has provided for twenty study participants. Each participant was interviewed separately in a setting to provide privacy. The researcher chose comfortable and easily accessible location for the participants. When it was necessary, the researcher was tried to be flexible during interview.

Key informant interviews were conducted with two organization officials. Two of the key informants were from RRDA PLHIV association of the town with large number of members and the pioneer, and Debre Markos town HAPCO. In this regard the issues rose about all the care and support provided for PLWHA, problems on care and support. In addition, the situation of care and support and its significance in prevention and control of HIV/AIDS in Debre Markos town were discussed.

4.6 Data analysis

The data was obtained through the abovementioned data collection instruments organized based on the research questions, objectives of the study and the questions were asked to the participants. In this process, transcriptions and coding of the information from interviews were primarily carried out to use the data systematically. Determining analytical themes began with through reading of each transcribe interview in order to identify categories from the data. Then, cases prepared according to the analytical categories. Based on the case, a detail interpretation was undertaken.

4.7 Ethical consideration

Ethical clearance was obtained from St. Marry University College, Addis Ababa research department. Then officials at different levels were communicated through the provided letter from St. Marry University College. Study subjects were informed about the purpose of the study and verbal informed consent was taken. In addition they were assured their full right to discontinue or refuse to participate at any stage of the study. For their confidentiality, names and house numbers were not recorded and their privacy also maintained.

CHAPTER FIVE

FINDINGS OF THE STUDY

This chapter discusses the findings of the study. It presents about the demographic information of participants related to sex, age, religion, ethnicity, educational status, employment status, average monthly income, marital status, number of children and housing condition. Subsequently HIV/AIDS related information like feeling when they know their HIV status, disclosure of HIV status, stigma and discrimination faced, and their recommendation to live a healthy life with HIV were assessed. In addition, their care and support related experiences are described.

5.1 Demographic Information /Characteristics of the Respondents

The study included twenty (ten male and ten female) participants. The major data was gathered from respondents using in-depth interview at Debre Markos Referral Hospital and Debre Markos Health Center. It was also supported by key informant interview with officials of Ransom Relief Development Association (RRDA PLHIV association) and Debre Markos town administration HAPCO.

Sex and age distribution, nine respondents (two male and seven female) are between the age of 25 – 34. Six respondents (four male and two female) were found between the age of 35 – 44, while the rest five (four male and one female) of the respondents were between 45 -49. Based on the data female participants are younger than their male counter parts. All of the respondents were *Amhara* in their ethnicity except one male respondent who was *Shinasha*.

The religious background of the participants revealed that nineteen (nine male and ten female) were Orthodox Christian, while the rest one male participant was Muslim. All of the respondents were disclosed their HIV Sero status.

Regarding the educational status five (two male and three female) participants were illiterate. One female respondent was from grade 1-4, six (three male and three female) respondents were from grade 5 -8, while the rest eight (four male and four female) were from grade 9-12. None of the participants graduated from or attended tertiary education.

Employment Status, ten (six male and four female) or about half of the study participants were employed in government or private institutions. Seven (two male and five female) respondents were daily laborers, two male participants were pensioned soldier and the remaining one female interviewee was unemployed.

The data obtained from the interviewee average monthly income and sex distribution shows that four (one male and three female) had below 200 ETB per month. Seven (three male and four female) respondents had average monthly income between 201 to 400 ETB. Four (two male and two female) participants were earned monthly from 401 to 600 ETB. Two participants (one male and one female) earned from 601 to 800 ETB per month. There were also three (male) participants earned above 800 birr per month. However; there was a big difference on earning of average monthly income from none (zero) one female to 4500 ETB (one loader operator male). Females average monthly income was very much less than their male counter parts.

Among the participants who have interviewed, their marital status show that five (three male and two female) were single. Eight (six male and two female) participants were married. Four

(female) interviewees were divorced. Three (one male and two female) participants were widowed.

Five participants (three male and two female) had no child. Three (one male and two female) respondents had one child. Eight (four male and four female) respondents had two children. There were also four (two male and two female) interviewees had three children.

About housing condition, all of the study participants have no their own house. Half of the respondents (six male and four female) were lived from private rented house. Three (all female) live on government rented (kebele houses). Seven (four male and three female) were lived with their families.

Regarding HIV/AIDS diagnosed time five of the respondents (one male and four female) were tested before nine years, seven (five male and two female) participants were known their HIV status before six to eight years. In addition, eight (four male and four female) respondents were tested before two to five years. There were one male and one female lived twelve years after they were known their HIV sero status while the shortest time was two years (one male and one female). Among the research participants except one female nineteen respondents were started ART treatment.

Half of the interviewees (three male and seven female) were faced stigma and discrimination but half (seven male and three female) were not faced.

5.2 HIV/AIDS Related Information

The findings regarding HIV/AIDS related information categorized in to five major themes. The first part is feeling and thought when they know their HIV status. The second part is participants

feeling living with HIV/AIDS. The third part of the findings deals with participants understanding about HIV/AIDS. Stigma and discrimination issue is the four part of the finding. At last, participants recommendation on positive living with HIV.

Feeling and thought when they know HIV status

Thirteen participants (seven female and six male) were reported that, they were negatively affected by the result, when they knew their sero positive status for the first time. And some of the participants did not accept the result and tested in other health institutions. However, seven participants (four male and three female) reported that they did not worried about the result. For instance a 30 year old woman stated the situation as she was “...*mad and unconscious for about three months, did not talk with any one, cried and tensioned and feeled hopeless.*”

Another women participant of age 47 also said

It was very challenged in my life, especially my three children issue made me to lose my consciousness, because there was no one to support them. Before ten years, that I know my sero status was too difficult; even there was no ART treatment as today. In addition, my three children HIV status also other critical issue that made me sleepless and worried me a lot, but I forget everything after they were free from HIV.

In addition a 43 year old man said the situation that,

It was too difficult even to tell and to remember. It made me simply to speak loud and mad; even I didn't tell my sero status result to my wife. She knows the result after two month; the time was too difficult even it is not necessary to remember the situation.

There was also participants' response difference for their positive sero status before and after the introduction of the ART drugs. Before the beginning of ART treatment, when anybody knows his/her sero status positive they became hopeless, depressed and even unconscious. However, after the treatment started the society understanding improved, then stigma and discrimination minimized. PLWHA considered them as they can live as others. And the response to their sero positive status was changed.

In contrast almost one third of the participants of this study did not worry about their sero status in the first time when they told by medical personnel. This was because of their previous information about sexual partner's positive HIV status and/or the symptom of the disease on themselves. As a result, they visited health institution expecting positive HIV result. Hence, they were ready to accept the result as positive. Among these a 35 year old unmarried man said that,

I have discussed for three days with my girl friend /sexual partner/ and then I went to the hospital after I have convinced myself as positive and I can live by taking ART. As a result I was positive and I was not worry about when I was positive. Then, I started the treatment.

The other 49 year old HIV positive man also said that *"I didn't say anything about it because I believed that the disease comes by God and accept it simply without any worry."*

In addition the other 38 year old widowed said *"When I knew my HIV positive sero status, I didn't fear because my husband was died because of HIV/AIDS. Hence, I have convinced myself and tested by myself without anybody support."*

PLWHA feeling about living with HIV/AIDS

PLWHA felt positively or negatively about their HIV sero positive status. Six participants (three male and three female) were felt negatively, while fourteen (seven male and seven female) were felt positively, since the presence of ART considered themselves can live as anybody live.

Among the negatively felt of being with HIV/AIDS explained *“The presence of HIV/AIDS in my blood created unpleasant condition and thinking the disease made me feel inferior.”*

In addition others also said *“I have encountered the virus from my husband hence I always regret about that.”* The other woman also said

I have three children I earned income by selling local alcohol ‘‘ Tela’’ however after I was HIV positive no one come and drink. As a result, I have got a problem to grow my children and suffer a lot. This is because of HIV/AIDS. So, I hate the presence of the virus in my blood.

Besides, female respondents, the male counter parts also replied that, they were felt negatively. They stated that, they were felt lack of self-confidence, being tensioned, considered themselves physically weak to do things actively as HIV negative people did. In this regard a 43 years old man stated that;

Being HIVpositive has its own negative impact on my life. These negative impacts were lack of energy at the time of work, reduce CD-4 count, loss of physical functioning and finally reduced income. It is too difficult, hence even I didn’t wish to my enemies.

In the contrary fourteen (seven male and seven female) participants of this study were reported that living with HIV/AIDS were not considered as disease. Because they considered themselves

as normal individual and they can do and live what others do and live until the presence of ART.

To mention some of their saying; A 35 years old man,

I didn't feel anything being HIV/positive since I can live as any individual can live. Even I didn't remember my sero status because the drug made me healthy, improve my physical functioning and income.

In addition one 30 years old woman felt that,

I didn't feel anything about the disease. There is a radical change in the society in understanding about HIV/AIDS. This gave me to be strong and optimistic, but there was a problem before a decade.

Participants Responses about HIV/AIDS

From the twenty respondents, fifteen (seven male and eight female) were reported that they were positively understood the notion of what HIV/AIDS for them. Whereas, the remaining five (three male and two female) were understood concept of HIV/AIDS negatively.

Those respondents who understood positively stated that, HIV/AIDS gave them education especially in relation to their religious life. Besides, it is a disease given by God. They considered as a common cold since they used the drug.

On the other hand, those respondents who understood HIV/AIDS negatively stated that, it is a disease that kills a human being before their actual death. It minimizes human capacity to do their duties; even one respondent strongly believed that once infected by HIV/AIDS no more to live.

Stigma and discrimination

The researcher forwarded question “have you faced stigma and discrimination?” for respondents. Based on this question participants were responded that there were stigma and discrimination and others believe the absence of HIV related stigma and discrimination. Half of the participants agreed on the presence of stigma and discrimination (seven female and three male) whereas the remaining half (three female and seven male) not believe and experience stigma and discrimination. As the data showed that the majority of female respondents were encountered stigma and discrimination. To cross check this question the researcher forwarded to explain briefly by whom and they said that by the community.

Accordingly 37 years old man stated that;

We have faced stigma and discrimination with my family. For instance, because of my HIV positive result nobody has come to drunk ``tela`` local alcohol that my wife sold. As a result of this, we suffered economically and socially.

In addition a 30 year old woman also said that, because of stigma and discrimination she and her families were banned to use toilet and out from rented house.

Recommendation how to live a positive living with HIV/AIDS

The researcher asked respondents to share their experience and to recommend others how to live positive life with HIV/AIDS. Based on this, the respondents shared and recommended the following:-

- Accept being with HIV/AIDS;
- Free from thinking about how, when and why infected with the virus;

- Accepting and implementing medical personnel's advice;
- Restricting oneself from drinking alcohol;
- Do not utilizing raw meat and milk;
- Proper and consistent use of condom;
- Treat timely opportunistic infections;
- Taking the drug properly as prescribed by the doctor;
- To be happy and free from internal tension at the time of unpleasant condition (upset);
- Praying to God according to their religion;
- Educating and counseling others;
- Being an exemplary for others;
- Keeping personal and environmental hygiene;
- Keeping and not transmit the virus to others by sharp materials;
- Not be hopeless/being hopeful/;
- Helping others;
- Think as others can live;
- Keeping oneself from chewing chat and smoking cigarette or free form any drug addiction;
- Prevent oneself from STI and timely treatment.

5.3 FINDINGS ON CARE AND SUPPORT

Care and support given for PLWHA

Among the in depth interview questions of care and support, of the situation of care and support given for PLWHA in Debre Markos town were responded different outlooks and answers.

Among the twenty participants (five male and six female) were responded that the care and support given for PLWHA in Debre Markos town was very good. They raised as an example the medical support without payment; the spiritual support given to the members of RRDA PLWHA association in every two weeks on Sunday; health educational support from medical personnel in positive living. In addition, although not enough the nutritional support from WFP, financial support to IGA, HBC by the volunteers, the psychological support by PLHIV themselves in their association and community support by minimizing stigma and discrimination.

In contrast six (two male and four female) respondents were replied that the care and support delivered to PLHIV was not enough. As they explained three kilogram wheat and one liter edible oil were not enough for a month, stigma and discrimination and house problems. There was also shortage of ART drugs in the last months of 2013. In addition, medical service was not attractive. In this regard 30 years old woman explained that;

Care and support is a game, it is simply talking without solving our problems. It is not a support by giving three kg wheat and one liter edible oil for a month. The community considered as we got a lot of care and support. There is inflation and the support is not enough.

More over 35 years old woman also said that,

Currently PLHIV have a serious problem of house, they faced a shortage of food by paying a house rent as a result women got to CSW. There are PLHIV that took the drug simply with water without any food. It is difficult to say there is a food support. There are lots of problems on PLWHA.

Two male respondents said that we didn't know the presence or absence of care and support of PLHIV in the town. They said that we haven't got it and we are simply taking the drug and go to our job.

Despite the above responses 35 years old man said that,

The care and support delivered to PLHIV made them dependent and developed a dependency syndrome.

Medical care and support

Medical and clinical care is one of the main care and support delivered to PLHIV. All of the participants had got medical care and nineteen of them also appreciate the service except one 30 years old woman has complained. Based on the medical care given to them and their wife five participants (three women and two men) responded that they had got HIV free children by PMTC (prevention mother to child) service.

According to the participants the other services delivered to PLHIV in medical care and support which includes free ART drugs, opportunistic infection treatment, counseling, health education, free payment treatment for the poor's, bed net, water pot, chemical water treatment, family planning, psychiatry, and CD-4 count. All PLWHA can't get OI treatment freely, rather it was for selected the poorest of the poor. There was a shortage of ART; PLHIV took the drug for a single day.

Psychosocial care and support

Psychosocial support has a great impact on the wellbeing of PLHIV. Among the twenty participants eighteen (eight male and ten female) responded they had got psychosocial support while two male respondents had not got it.

To describe some of them RRDA PLHIV association members had got from `mahiberekidusan` Sunday school spiritual support in every two weeks. Those who disclosed to their families and offices have got moral support and did not participate in hard work. As they said, if there is disclosure, there is psychosocial support because of community understanding to HIV/AIDS. The other supports were counseling from ART center by health professionals, ART adherence supports during monthly medical appointment. There is also HBC to the bedridden PLHIVs.

According to 30 years old woman,

I have wait up to now because of this support otherwise. If I did not have psychosocial support, I would be suicide myself. Therefore, psycho social support is essential for us.

In contrast two male respondents said we didn't get this supports because they were not disclosed their HIV status.

Economic support

Eleven (three male and eight female) participants responded that they had got economic support, whereas nine (seven male and two female) respondents had not got the support. To mention some of the supports food (which is not enough according to them and strongly recommended to increase the amount), initial capital for IGA, loan, house material (for IGA) most of the

participants especially females wanted to get initial capital to generate their own income to cover their livelihood.

Human rights and legal support

Among the twenty participants fifteen (six male and nine female) said that there were legal support; when PLHIVs faced legal problem, however those who got it were very few. But five respondents (four male and one female) said that there were no legal service support, it was simply present on the paper. According to them there were right to become the member of PLHIV association if anyone interested; as such most of them were the member of RRDA and Bezawit PLHIV association.

27 years old women said that;

One day two men come on my home and tried to rape me, they also took my tape recorder. They also throw my drug in the water and it became out of use. As a result; I have announced to the police and helped me to catch those guys. Even though I had got the legal support, I have changed my house, because I fear them.

The other example is that 30 years old women said that

A woman of my neighbor insulted me as a patient of AIDS `AIDSam. ` Hence I have taken the issue to the court of the town and then to the higher court. The higher court decided four month imprisonment on the woman.

Care and support problem

Among the twenty participants, fifteen (six male and nine female) responded that there were problems on care and support in Debre Markos town. Whereas, three (two male and one female)

respondents replied that there were no problem. The remaining two male respondents said we didn't know the problem of care and support in Debre Markos town.

According to the respondents the main problem was financial constraint. However they also rose:-

- Repeatedly support some individuals while other did not get any;
- Deliberate transmission of HIV to others;
- House problems /absence of kebele/ government house;
- House rent increment;
- Even though declined, there is stigma and discrimination;
- Insufficient and interrupted of food support;

The support focuses only to those who have children.

- Minimization of support from organizations /shortage;
- Insulting of kebele leaders when we asked kebele house;
- A patient waits one day to get three kilogram wheat and one liter oil with quality problem;
- Shortage of free treatment to PLHIV and died because of lack of money;
- PLHIV immediate aggressiveness and psychological problem;

Organizations involvement in HIV/AIDS care and support

The researcher asked participants to the involvement of organizations in addressing HIV/AIDS care and support. Based on the question they said that organizations that support them were;

RRDA, Bezawit women PLHIV association, HAPCO, OSSA, Missionary of Charity(Mother Theresa), MahibereKidusan, MuluWongel Church, and Health Office of the town.

In relation to organizations involvement twelve (three male and nine female) participants were appreciated their care and support activities. In the opposite two participants (one male and one female) said that organizations participations were not good. They explained their reasons that, the support delivered to PLHIVs were not enough particularly the food support. The remaining six male participants said that had no any information whether the organizations participations good or not.

However, key informant interview organizations responded that the number of NGOs in the town were very low. Even due to financial shortage of NGOs their participation in HIV/AIDS care and support decreased.

Significance of care and support in prevention and control of HIV/AIDS

The other interview question rose for participants were the significance of care and support in prevention and control of HIV/AIDS. As a result, seventeen (eight male and nine female) interviewees were responded that care and support has its own significance. When there is care and support, PLHIV announced their HIV positive then everybody knows them and cannot transmit to others. They did not migrate to other places to earn their livelihood and work in commercial sex. The spiritual as well as counseling support prohibit them to transmit to others. Even some PLHIVs who did not disclose their HIV status not transmit HIV/AIDS because of others support. Testimonial of PLHIV has also a good result in behavioral change of the

community. They also mention PMTCT service in medical care. At last the moral support result hopeful on PLHIV and a positive impact on its transmission.

Despite the above idea three participants raised that care and support has no any significance in prevention and control of HIV/AIDS. According to them the behavioral change of the community is the main one to prevent and control HIV/AIDS.

Unmet need of PLHIV in care and support

At last, to identify the gaps of care and support and unmet need of PLHIV, the researcher raised the question of their unmet need. As such they responded that five (four male and one female) did not need anything except the drug. All the participants were needed the availability of the drug. But, some of them have a threat on interruption of ART. Some participants have unmet needs like house, occupation, money, food, educational fee for children. The most unmet need was government (kebele) house.

5.4 Findings on key informant interview

Background of the key informant organizations

Ransom Relief and Development Association (RRDA) was established on November 2003 by technical and support of Zone HAPCO and CVM. It has been registered as Ethiopian Resident Charities consortium on November 2009 by EFDRE charities and societies agency with reference number 0326. PLHIV during the establishment were forty two female and twenty three males and total of sixty five members as Beza People Living with HIV/AIDS Association. But currently members of the association reached a total of 2280 (of these 1596 females). RRDA

envisions seeing a society free of HIV/AIDS where people living with HIV are empowered, promoted and children play better life. RRDA exists and operates so as to prevent the spread of HIV/AIDS and reduce its impact through intensified scale up and comprehensive programs with active participation of all its members and with special focus on meaningful involvement of PLHIV and their families with empowerment. It works to enhance the meaningful participation and listened voice of PLHIV at higher levels through capacity building, HIV/AIDS advocacy, resource mobilization and organizational management.

The general objective is to enhance the capacity of RRDA and its constitute through effective empowerment to improve the quality of life of PLHIVs, OVCs and their families by the existing prevention, care and support and treatment services.

In addition, Debre Markos town administrations HAPCO Joint Planning, Monitoring and Evaluation officer was the other key informant organization. It was established in 2003 as coordinating body of HIV prevention and control in the town. But now it is under Health and HIV office as a section. Hence, it coordinates government sectors, NGOs and PLHIVs and their association in prevention, and care and support.

As a result, the researcher made the above mentioned two organizations as part of key informant interview, because the organizations have direct relationship with PLHIV care and support and other activities on them. Accordingly there are four themes of findings such as; first care and support delivered for PLWHA, second problems on care and support, third the situation of care and support in the town, and fourth outcomes of care and support.

Care and support delivered for PLWHA

According to RRDA a lot of care and support delivered to PLWHA mostly by PLWHA and by other organizations in cooperation. Hence, psychological support HBC, screen potential PLHIV in IGA& food support, facilitate to get spiritual support for its members, awareness in ART adherence, invited health professionals to give health education, facilitate to members to get free scholarship, job opportunity, clothing and hygienic resources like soap. As much as possible RRDA supports for the wellbeing of its PLHIV members.

In addition, HAPCO also coordinate PLHIV to get food support, financial, training on income generating and awareness creation on positive living with the virus.

Problems on care and support

According to RRDA the problems on care and support PLHIV were a lot but the main one was aid agents stop their support due to absence of budget. Others were increased number of PLHIV, small number of volunteers and ART promoters in HBC, even absence of budget to running cost of PLHIV umbrella RRDA, and dependency syndrome of PLHIV. The interviewee described also members were fear about the interruption of the drug due to shortage of fund from the main donors.

The informant from HAPCO also described the problems of care and support. The interruption of global fund, which was the main engine in HIV/AIDS prevention as well as care and support, small number of organization (NGO) in the town, limited financial support from NGO, problems of partnership among organizations, the decrease of food support from WFP, dependency syndrome on PLHIV and attitude problem to work and change their life are some.

The situation of care and support in the town

According to RRDA's nine month report of 2006 fiscal year (2013/2014) care and support were delivered by different governmental and NGO to its members. The care and support were through creating job opportunities; vocational training by back to work program of save the children and Global fund and presenting working initial capital of Birr 4.000 from Global fund. Moreover, three hundred sixty three (forty four male and three hundred nineteen female) got HBC by thirty HBC volunteers. There were also food support for eight (one male and seven female) 200 ETB in quarter from Global fund. Psychosocial support was delivered for one thousand three hundred eighteen (five hundred sixty eight male and seven hundred fifty female).

According to HAPCO nine month report of 2006 budget year (2013/14) including the above mentioned RRDA the following care and support delivered to PLHIV in the town. These were 2011 (male 337 and female 1674) medical care, food support, and psychosocial support. Seven (three male and four female) PLHIV have got house support (shelter), 299 (29 male and 270 female) and 276 (19 male and 257 female) have got IGA training and IGA initial capital respectively. Those who got HBC were 4741(298 male and 4443 female). It was not reported legal service support.

The above care and support to PLHIV mostly delivered by other organizations especially those request budgets. In the past HAPCO also delivered care and support with hundred thousands of ETB funded from Global fund and others. But there was no budget for care and support in this annual budget year. HAPCO also said that food support from WFP would be interrupt in the near future due to shortage of budget.

Outcome of care and support

According to RRDA care and support have a multipurpose on PLHIV and in HIV/AIDS prevention and control. To mention some of the main ones; improve PLHIV health, strengthen their income and productivity, decreased morbidity and AIDS mortality. In addition, improve their psychological wellbeing and social participation.

HAPCO also described its significance because of PMTC service contributes to get HIV free children; promotes ART adherence, because of PLHIV parents wellbeing and productiveness their children attended school. According to their observation, HIV/AIDS dependency syndrome minimized and developed interest to work to be self-reliant.

CHAPTER SIX

DISCUSSION

This study assessed HIV/AIDS care and support to PLWHA in Debre Markos town, Ethiopia. The in-depth interview and key informant interview data collection techniques were salient to understand care and support delivered for PLWHA in the town. The findings of the study were analyzed and discussed in relation to the research questions.

HIV/AIDS care and support provided to PLWHA

Medical and Clinical care

According to this study medical and clinical care was the main care and support delivered for PLWHA, which was given for all participants. And out of twenty participants nineteen of them appreciate the service. The services delivered to PLWHA were ART drug, OI treatment, counseling, health education, family planning, bed net, water pot, chemical water treatment and psychiatry service. All OI treatment was not delivered with free payment to PLWHA, unless they were identified as the poorest of the poor by kebele leaders for free service. PLWHAs that had ART follow up faced shortage of ART. Hence they came to take the drug daily before six months of the study period. The same study conducted in Arba Minch medical and nursing care was not according to the continuum of care and entirely dependent on external financial support. (Tadesse et al., 2011).

Psychosocial care and support

Among the participants majority were responded that they had got psychosocial support mainly spiritual support, moral support if there was disclosure, health professional counseling, HBC.

However, the levels of psychosocial support to PLHIVs were not adequate. PLHIV to get psychosocial support disclosure of their HIV sero status is prerequisite. The support saves patients life, and the wellbeing of them and their families. It has also a direct result in prevention and control of HIV/AIDS. The study conducted in Arba Minch revealed that 128(56.6%) participants said they had obtained counseling, more than half of the sample reported spiritual support from religious group, while the remaining participants 104(46%) were given community moral support as part of psychosocial support. (Taddesse et al., 2011). And another study conducted in Gahana showed that even though PLWHA have better health outcomes with ART they still faced psychological isolation and condemnation from their family, friends and society (Black stock, 2005).

Economic support

Half of the study participants were had got economic support. The supports in this regard were food support which was insufficient, initial capital for IGA, loan and house materials. The economic supports delivered to beneficiaries were not adequate. The financial shortage of organizations results to decrease the support. In addition the small numbers of organizations that involve in economic support in the town also result to the minimization of economic support. The same study done in Arba Minch result showed that 58(25.7%) of the participants had obtained material support this includes agricultural materials and seeds, educational and clothing materials, and in different activities of income generating activities, 144(63.7%) had obtained food support.

Human rights and legal support

In this study majority of respondents said that there were legal supports, when they faced problem. However, those who hadn't got an actual support were very few. Awareness of PLHIV on human right and legal support was important to utilize the service. In contrary, the study conducted in Arba Minch none of the association organizations that were included in the study provided human rights protection and guidance or legal support to their clients. (Taddess et. al., 2011)

Problems of HIV/AIDS care and support

In this study the majority of the respondents were reported problems on care and support. The problems were so enormous. Among those problems, the main one was financial problem. These problems were not relied on organizations only, but also in the community and PLHIV themselves. The same study of Arba Minch showed that, care and support activity provided were minimal and most of the respondents were not getting the palliative care. Psychosocial, legal and human right services were widely neglected or were not given due attention by almost all care givers as part of the standard of care and support. In addition, little attention but can have a major impact in the implementation of care and support activities is the lack of client referral and linkage between caregivers and organization. The major challenges of care and support, providing organizations were facing financial and technical limitation and governmental institutions were limited to only few components of care and support (Tadesse et al., 2011).

The needs of people living with HIV/AIDS

The data in the in-depth interview depicts that most of the participants had unmet needs of house, occupation, money and food. Among these houses was the most unmet need of them. The study

conducted in Addis Ababa revealed that major needs of PLHIV were nutritious food, access to their own or kebele house, human right or legal need (Zelalem, 2007). The other study conducted in Arba Minch showed that the need for food, financial constraints, training of family care givers, psychosocial support were unmet need of PLHIV(Tadesse et al., 2011).

Organizations involvement in addressing HIV/AIDS care and support

In this study the result showed that the presence of few organizations in care and support. Even, their support was not enough to solve the problems of PLHIV, because of their limited resources and occasional support. The other study elsewhere in Ethiopia showed that the governmental organizations were mainly involved in the provision of psychosocial, medical and nursing care; while the NGOs, were mainly involved in the provision of socio economic and psychosocial support (Tadesse et al., 2011).

CHAPTER SEVEN

CONCLUSION AND RECOMMENDATION

7.1 Conclusion

This study was conducted to assess PLHIVs at Debre Markos town and identified those problems of care and support. Generally among the four components of care and support the availability of medical and clinical care and psychosocial support particularly spiritual support were good. Medical and clinical cares were mostly with free payment. But, there was a threat on PLHIVs on the sustainable supply of ART.

Even though, there were economic support to PLHIVs by different organizations, the support was not sufficient to solve their problems. In addition, human right and legal supports were not practically delivered to PLHIVs.

Mostly care and support in the town depend on external financial donation. This donation is decreasing, hence the care and support delivered to PLWHA minimized and not in sustainable manner.

Most of the participants of the study had their unmet need of house /shelter/, occupation, money and food. Organizations involvement in care and support were very low. Even their activity on care and support was not sufficient to solve the problems of PLHIV.

7.2 Recommendation

Based on the findings of the study the following recommendations are made.

- There were not sustainable care and support as well as all components were not included. Hence, governmental organizations and NGOs that are participating in care and support

have strengthen and improve all components of care and support in sustainable manner up to the level that best fits the needs of PLHIV.

- The care and support were given to PLHIV small amount of economic support and did not change their life style permanently. Therefore, to improve PLWHAs economic and their quality of life sustainably organizations focus on to involve PLHIVs in income generating activities.
- The findings of the study showed that, there was unmet need of housing for PLHIVs. So, government and NGOs that are participating on care and support better to access housing need for PLHIVs.
- Even though, there were small number of organizations that involved in care and support, the coordination between them was weak. Hence, organizations that involved in care and support give emphasis on partnership to provide efficient services and to coordinate strongly.
- Most of HIV/AIDS control and prevention activities were donated from foreign Global Fund, for instance the budget of HAPCO. However, at this time their support is declining due to shortage of fund. As a result of this, those who need care and support from them are affecting and will be affected. Therefore, the dependency on foreign donation of care and support should be minimized and created or replaced by another internal source by the government as a means to solve the problems of PLHIV.
- There were lack of awareness in employing human right and legal service. So, creating awareness to PLHIVs and their families on human right and legal service support to utilize effectively by care support providers through training and education.

- The study was not assessed fully all the problems of care and support. Hence, the researcher recommends other researchers further conducting on the topic.

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Annexes: 1 Informed-Consent form

**INDIRA GANDHI NATIONAL OPEN UNIVERSITY SCHOOL OF SOCIAL WORK
STUDY ON ASSESSMENT OF HIV/AIDS CARE AND SUPPORT IN PEOPLE LIVING
WITH HIV/AIDS AT DEBRE MARKOS TOWN.**

Information sheet:

Good morning/afternoon. My name is YigzawTeshome

First of all I would like to thank you for your time.

I am working research for the partial fulfillment of Master's Degree in Social Work at **Indira Gandhi National Open University School of social work**

The main purpose of the study is to assess HIV/AIDS care and support in people living with HIV/AIDS. I am inviting HIV positive people between the ages of 15 and 49 years to contribute for the study and you are one of them who have been selected to participate in this study. The study will not cause any harm to you except giving the information. Therefore, you are kindly requested to participate in this study and provide the information required from you.

I would like to ask you a few questions if I may, but you can refuse to answer any question I ask. You may end the interview at any time. You can also refuse to participate in the study entirely. Your refusal will not restrict you from obtaining the required medical care when you need. The interview will last approximately 30-60 minutes. Your responses will be kept confidential and there will be no way of linking your individual responses to the final results of

the study findings. I would like to inform you that the responses that you provide to the questions are very essential, not only, for the successful accomplishment of the study, but also for producing relevant information which will be helpful in the planning and implementation of intervention activities to improve your reproductive and Family Planning service needs.

Are you willing to respond to the questions? 1. Yes -----; proceed with the interview.

2. No-----; thank you and End.

ANNEX 2: In-depth Interview Guide

A. Demographic Information

1. Code _____
2. Sex Male----- Female-----
3. Age _____
4. Religion _____
5. Ethnicity _____
6. Educational Status _____
7. Work position _____
8. Average monthly Income -----
9. Marital Status _____
10. No of children _____
- 11 .Condition of housing (rented private, own, and rented government& number of rooms) with whom he/she lives?

B. HIV/AIDS Related Information

1. When have you been tested -----?
2. What did you feel and thought when you know you are HIV positive?
3. Did you start ARV treatment? Yes----- No-----
4. If yes for how long? -----

4. Have you disclosed your HIV status?
5. If yes, for whom you have disclosed your HIV status?
6. What is your feeling of living with HIV/AIDS?
7. What is HIV/AIDS for you?
8. Have you faced stigma and discrimination? Yes----- No-----

If your answer is yes explain briefly by whom?

9. What would you recommend to someone on how to live with HIV? Living a healthy life with HIV?

C. Care and Support related Questions

1. Tell me about the care and support given for PLWHA in Debre Markos town?
2. What kind of services got from health institutions?
3. Have you got psychosocial support? Yes----- No-----

If your answer is 'yes' mention some of them?

4. Is there a support to strengthen your economy? Yes----- No-----

If your answer is 'yes' elaborate some of them?

5. What is the situation of care and support in relation to human right and legal service?
6. What is the problem of care and support in Debre Markos town?
7. What are the organizations participated in care and support for PLWHA?

- What is there participation?

8. What is your comment regarding care and support ?

9. What is the significance of care and support in prevention and control of HIV/AIDS?

10. Tell me your unmet need in care and support.

Annex 3. Key informant guide (for organization Officials)

1. Name of the organization _____.
2. Address _____.
3. Position of the respondent _____.
4. Organizations objective and main duties _____.
5. What is the contribution of the organization in HIV/AIDS prevention and control?
6. What kind of care and support delivered for *PLWHA*?
7. What is the problem, in relation to care and support?
8. How much budget allocated for care and support?
9. What is the situation of care and support in the town?
10. Elaborate the outcome of care and support.
11. What is the experience of organizations coordination in care and support?

አባሪ 1: የግንዛቤናየፈቃደኝነትመጠየቂያቅጽ

በኢንድራጋንዲናሽናልኦፕንዩኒቨርሲቲድሀረምረቃየሶሻልወርክትምሀርትቤት

የጥናቱመረጃቅጽ

የጥናቱርዕስ:- በደብረማርቆስከተማየኤችአይ ቪ/ኤድስድጋፍናክብካቤንመዳሰስ

ጤናይስጥልኝ!!

ስሜ:-ይግዛውተሾ መይባላል::

በኢንድራጋንዲናሽናልኦፕንዩኒቨርሲቲድሀረምረቃየሶሻልወርክትምሀርትቤት

አጥኝነኝ::

የዚህጥናትዋናአላማበደብረማርቆስከተማየኤችአይ

ቪ/ኤድስድጋፍናክብካቤንመዳሰስነው::እርስዎበጥናቱእዲሳተፉተመርጠዋል::

ጥናቱየሚያደርሰውምንምዓይነትጉዳትየለም::ዕርስዎንበተመለከተመረጃእጠይቅወታለሁ::ቃ

ለምልልሱበግምት

h30-60

ደቂቆችይፈጃል::እርስዎየሚሰጡንመረጃሚስጢራዊነቱሙለብሙለብተጠበቀነው፣የእርስዎስም

አይመዘገብም፤

እርስዎበጥናቱየመሳተፍምሆነያለመሳተፍሙብትያለዎትሲሆንጥያቄዎችንያለመመለስወይምየ

ማቋረጥሙብትዎየተጠበቀነው::ነገርግንእርስዎየሚሰጡንመረጃየጥናቱንአላማለማሳካትናየኤች

አይ

ቪ/ኤድስድጋፍናክብካቤአሰጣጥላይየፖሊሲቀረጻናፕሮግራምማሻሻያለማድረግሆነከቫይረሱጋር

የሚኖሩሰዎችንተጠቃሚለማድረግከፍተኛጠቀሜታአለው::

አሁንም በድጋሚ ላረጋግጥልዎት የምፈልገው ነገር የእርስዎ ስም በዚህ ቅጽ ላይ አይመዘገብም፣ የሚሰጡን መረጃም ሚስጢራዊነቱ ፍፁም የተጠበቀ ሲሆን መረጃው ለጥናቱ ዓላማ ብቻ ይውላል።

በጥናቱ ለመሳተፍ ፈቃደኛ ነዎት?

1. አዎ-----

2. አይደለሁም-----

አዎካለ፡ አመሰግናለሁ! ቃለ-ምልልሱ ይቀጥላል።

አይደለሁምካለ፡ አመስግነው ደንበኛውን አሰናብተው ወደ ሌላ ተጠያቂ ይለፉ።

አባሪ 2: መጠይቅ

ሀ. የግለሰብ/ዊ መረጃ

1. ኮድ _____
2. ያታ ወ _____ ሴ _____
3. ዕድሜ _____
4. ሃይማኖት _____
5. ብሔር _____
6. የትምህርት ደረጃ _____
7. የስራ ሁኔታ _____
8. አማካይ የወር ገቢ _____
9. የጋብቻ ሁኔታ _____
10. የልጆች ብዛት _____
11. የቤት ሁኔታ (የግል ኪራይ የግል ከመንግስት ኪራይ ___)
የክፍሎች ብዛት _____ ከማን ጋር ይኖራሉ? _____

ለ. ከኤችአይቪ/ኤድስ ጋር የተያያዙ መረጃዎች

1. ተመርምረው ራስዎን ያወቁት መቼ ነው?
2. ተመርምረው ኤችአይቪ/ፖዘቲቭ ሲሆኑ ምን ተሰማዎት? ምን አሰቡ?
3. የፀረ-ኤችአይቪ መድኃኒት ጀምረዋል? አዎ----- የለም-----
4. ኤችአይቪ/ፖዘቲቭ መሆንዎን ለሌላ ሰው አሳውቀዋል? አዎ----- የለም-----
5. ለጥያቄ 4 መልስዎ አዎ ከሆነ ኤችአይቪ/ፖዘቲቭ መሆንዎን ያሳወቁት ለማንነው?
6. ኤችአይቪ/ፖዘቲቭ መሆንዎ ምን ይሰማዎታል?
7. ኤችአይቪ/ኤድስ ለእርስዎ ምን ድንኳን ነው?
8. ማግለልና መድልዎ አጋጥሞዎት ያውቃል? አዎ----- የለም-----
 መልስዎ አዎ ከሆነ በማን? እባክዎትን ቢያብራሩልኝ?
9. አንድ ሰው ከኤችአይቪ/ኤድስ ጋር እንዴት መኖር እንዳለበት ምን ይመክራሉ?
 ጤናማ ህይወት ከቫይረሱ ጋር እንዲኖር

ሐ. የድጋፍና ክብካቤ ጥያቄዎች

1. በደብረማርቆስ ከተማ ቫይረሱ በደማቸው ውስጥ ያለባቸው ሰዎች የሚሰጠው ድጋፍና ክብካቤ ምን ይመስላል?
2. በህክምና ተቋማት ምን ምን ዓይነት አገልግሎቶችን ያገኛሉ?
 የአገልግሎት አሰጣጡ ሁኔታ እንዴት ይገልጹታል?
3. የስነልቦናና የማህበረሰብ ድጋፍ ያገኛሉ? ምን ምን ናቸው?
4. የኢኮኖሚ አቅምዎትን የሚያጠናክር ድጋፍ አግኝተው ያውቃሉ? አግኝተው ከሆነ ቢያብራሩልን?
5. ቫይረሱ በደማቸው ውስጥ ላለባቸው ሰዎች ሰብአዊ መብትና የህግ ድጋፍ አሰጣጥ ምን ይመስላል?
6. በደብረማርቆስ ከተማ ከድጋፍና ክብካቤ ጋር ተያይዞ ያለው ችግር ምን ድንኳን ነው?
7. ቫይረሱ በደማቸው ውስጥ ላለባቸው ሰዎች ድጋፍና ክብካቤ እያደረጉ ያሉት አካላት እነማን ናቸው?

ተሳተፏቸውስምንይመስላል?

8. በድጋፍናክብካቤያለዎትአስተያየትምንድንነው?

9. ኤችአይ ቪ/ኤድስንበመከላከልናበመቆጣጠርድጋፍናክብካቤምንአስተዋጽኦአለው?

10. በድጋፍናክብካቤእንዲሟላልዎትየሚፈልጉትያልተሟላፍላጎትዎምንድንነው?

አባሪ 3.ለተቋማት ኃላፊዎች የቀረበ ጥያቄ

1. የድርጅቱ ስም-----

2. አድራሻ -----

3. የሰራድርሻ-----

4. የድርጅቱ የላማና ዋና ዋና ተግባራት ምን ድንገቶች ናቸው?

5. ድርጅቱ በኤች አይ

ቪ/ኤድስ መከላከልና መቆጣጠር ዙሪያ እያደረገ ያለው አስተዋጽኦ ስምን ይመስላል?

6. ቫይረሱ በደማቸው ውስጥ ላለባቸው ሰዎች እያደረገ ያለው ድጋፍና ክብካቤ ስምን ድንገቶች ናቸው?

7. ከድጋፍና ክብካቤ ጋር ተያይዞ ያለው ችግር ስምን ድንገቶች ናቸው?

8. ከበጀት አኳያ ለድጋፍና ክብካቤ ስምን ያህል መድቧል?

9. ድጋፍና ክብካቤ በከተማው ያለበት ሁኔታ ስምን ይመስላል?

10. ድጋፍና ክብካቤ ያመጣው ውጤት ካለበት ገለጽ?

11. ድርጅቶች በድጋፍና ክብካቤ ተቀናጅቶ በመስራት ያለው ተሞክሮ ስምን ይመስላል?