

NEEDS ASSESSMENT OF PLWHA IN ADDIS ABABA

Assessment conducted by

Family Health International-Ethiopia

in collaboration with the

Addis Ababa HIV/AIDS Prevention and Control Office

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PREFACE

This report summarizes many, many discussions with people living with HIV/AIDS on their needs, the services they use, stigma and discrimination they have experienced, and recommendations for a strengthened response. Discussions with community representatives complemented the information received from people living with AIDS. We thank the organizations Mekdim-Ethiopia and Dawn of Hope, and the Addis Ababa HIV/AIDS Prevention and Control Office for their support and assistance in conducting this assessment. This PLWHA needs assessment is one of five assessments conducted in Addis Ababa to inform efforts for an expanded and comprehensive response to AIDS in the region. The assessments were conducted by Family Health International in collaboration with the Addis Ababa HIV/AIDS Prevention and Control Office and stakeholders involved in the response. Funding for these assessments was received from USAID and CDC.

It is clear that the impact of HIV/AIDS prevention, care and support efforts is enhanced by engaging people living with HIV/AIDS. This report shows that people living with HIV/AIDS WANT to play a more active and central role in the response to AIDS.

HIV/AIDS prevention, care and support efforts are only effective if they are designed to address what the beneficiaries of our program efforts want and the needs they prioritize. Understanding how beneficiaries perceive and utilize existing support services is essential. It helps us learn from past experiences, tailor programs to meet perceived needs, and maximize the efficacy of program efforts.

The discussions started during the dissemination of the preliminary findings of this assessment already have led to a dynamic of enhanced engagement of PLWHA in the response to AIDS in Addis Ababa. We look forward to working with you – PLWHA and other partners in the response to AIDS – to strengthen the PLWHA engagement in the continuum of HIV/AIDS prevention, care and support.

Dr. Ashenafi Hailu

Head

Addis Ababa HIV/AIDS Prevention and Control Office

Francesca Stuer

Country Director

Family Health International/Ethiopia

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ACRONYMS

AACAHB	Addis Ababa City Administration Health Bureau
AIDS	Acquired immune deficiency syndrome
BCC	Behavioral change communication
CBO	Community-based organizations
EMSAP	Ethiopia Multi-Sectoral AIDS Project
ETB	Ethiopian birr
FDRE	Federal Democratic Republic of Ethiopia
FGD	Focus group discussion
HBC	Home-based care
HIV	Human immunodeficiency virus
IEC	Information, education and communication
MMM	Medical Missionaries of Mary
MoH	Ministry of Health
NAC	National AIDS Council
NGO	Non-governmental organization
OSSA	Organization for Social Service for AIDS
PLWHA	People living with HIV/AIDS
SAHRE	Society for the Advancement of Human Rights Education
VCT	Voluntary counseling and testing

DEFINITIONS

<i>Idir</i>	A community burial and support association
<i>Kebele</i>	The smallest administrative unit under the <i>wereda</i>
<i>Wereda</i>	Administrative unit (equivalent to district)

EXECUTIVE SUMMARY

In Ethiopia, the government policy on HIV/AIDS (human immunodeficiency virus/acquired immune deficiency syndrome) is geared towards the implementation of preventive programs and the provision of rehabilitative services to those already infected and affected by the virus. The care and support system constitutes the core of the rehabilitation component of the policy. Currently, various governmental and non-governmental agencies as well as community-based organizations (CBOs) are actively involved in providing some form of care and support services.

Within this framework, the present study seeks to identify the principal needs of people living with HIV/AIDS (PLWHA) and their families from the insider's perspective. In addition, as part of its main purpose, the study provides a profile of the care and support networks currently in place in Addis Ababa as perceived by PLWHA. Barriers and challenges encountered by PLWHA as they try to access care and support services are examined. Moreover, recommendations made by individuals and groups of participants concerning necessary improvements and refinements to the administration of care and support services are also considered.

On the basis of information obtained from PLWHA and community representatives, the most important needs of PLWHA were identified as emotional and psychological, physical and socioeconomic, clinical and health care, and legal and human rights.

PLWHA focused on their emotional and psychological well being as their most important need. They craved social acceptance and empathy to help them deal with the traumatic nature of their situation. They also demanded that the government give greater attention to PLWHA, so that the conditions they faced could be better addressed and their various requirements duly satisfied. Despite the presence of a national HIV/AIDS policy with specific provisions for PLWHA, the general feeling expressed by individual and group discussion participants was that these measures did not go far enough. Participants felt that rehabilitation aspects of the policy had received only marginal attention. As a result, existing care and support services remained inadequate in the face of growing demands.

Second on the list of priority needs were the physical and socioeconomic requirements of PLWHA. These needs had their origins in poverty and low standards of living, and were further compounded by the HIV-related failure of the immune system. Essentially, physical and socioeconomic support encompassed the provision of nutritional supplies, shelter and clothing. Nutritional support emerged as a prominent need since it played an important role in strengthening the body's resistance to the disease and thus averting the early occurrence of death. No less important was the need for adequate and secure housing. Numerous cases of mistreatment (intentional or otherwise) experienced by PLWHA were connected to the loss of their dwellings, inability to find a house or similar hardships. AIDS orphans were reported to be at particular risk in this regard; quite often, these orphans were left homeless when their parents died. Reportedly, some renters (public and private alike) were forcing helpless orphaned children out of their shelters, once their parents were dead. To make matters worse, this was not the only problem faced by AIDS orphans. Dislodged from their once secure abodes, the children affected by AIDS often found themselves vulnerable to various forms of abuse, including sexual assault in the case of orphaned girls. Homelessness generally forced the orphaned children out onto the streets where they were exposed to many problems, including a high risk of contracting HIV/AIDS.

Another priority need concerned the future prospects of children whose parents were living with the virus. At the time of the study, circumstances in Ethiopia promised no more than a slow death to HIV positive individuals. With this expectation in their mind, parents living with HIV/AIDS expressed serious concerns for the future of their children. The parents described fears that their children would suffer after their deaths because they would have no means of supporting themselves. These fears were robbing the parents living with HIV/AIDS of their peace and stability of mind. Parents in this situation underscored the need to prepare their children for a productive life in their absence. They felt vehemently that such needs could be addressed adequately by providing the children with sufficient job-oriented training while at least one of their parents was still alive.

Similarly, the need of PLWHA for affordable, comprehensive and specialized medical services was emphasized. For the health services to be attuned to the needs of PLWHA

and AIDS orphans, they needed to include the treatment of opportunistic infections, counseling and psychological support, and home-based nursing and treatment.

Finally, protection of the legal and human rights of PLWHA and AIDS orphans was identified as one of their most important expressed needs. Pertaining to this, the Federal Democratic Republic of Ethiopia's (FDRE) existing HIV/AIDS policy document Article No. 2.5 stated that one of its objectives was to safeguard the human rights of PLWHA and avoid discrimination against them. Nevertheless, in contrast with the text and sentiment of this policy article, PLWHA had often experienced gross violations of their basic human rights. The injustices faced by PLWHA ranged from acts of social discrimination and ostracism to outright denial of property inheritance and transfer rights, and the infliction of verbal, physical and sexual forms of abuse. PLWHA vehemently lamented the fact that their adverse situation was aggravated more by the failure of the existing legal system to protect their rights, than by their medical condition.

Perceptions of PLWHA of the existing care and support services for PLWHA in Addis Ababa were also assessed. Beneficiaries of the existing services indicated clearly that two associations of PLWHA (namely, Dawn of Hope and Mekdim Ethiopia) made the greatest contributions to the care and support activities carried out in the city. The major aspect of the services rendered by these associations constituted professional HIV/AIDS counseling and psychological support. Other types of services provided by the associations included material support, orphan care, legal support, home-based care (HBC) and financial assistance to cover medical costs.

In particular, HBC was highlighted as a major focus area for these associations; it was seen as an area that was gaining ever-greater importance. The emphasis placed on HBC by the associations of PLWHA had advantages from the perspective of both the care providers and recipients. First, jobs created by this service allowed HIV positive members of the associations to find meaningful employment. Secondly, shared experiences and sentiments enabled these HBC providers to be particularly sympathetic and supportive to those they were employed to serve.

Community members in focus group discussions (FGDs) reported that government and non-government agencies, CBOs, youth associations and anti-AIDS clubs played an important role in the provision of care and support services to PLWHA and their families.

Voluntary counseling and testing (VCT), which constitutes an important part of the continuum of care and support services, was in particular provided by a number of indigenous and international non-governmental organizations (NGOs). Key informants and FGD participants identified the NGOs that were actively involved in this type of service as: Mary Joy through Development, Medical Missionaries of Mary (MMM) Counseling and Social Service Center, Hiwot Tesfa, the Organization for Social Service for AIDS (OSSA) and CARE Ethiopia. These agencies were providing VCT free-of-charge to orphans and vulnerable children, whilst other clients were charged only token amounts.

Orphan care, in the form of material and financial support, was another major type of service provided by these NGOs. Moreover, a similar type of support in the form of food, clothing and cash donations was being provided to PLWHA by non-governmental agencies working in the area of HIV/AIDS.

Wereda HIV/AIDS councils were identified as important government bodies in the provision of care and support services. These councils used resources provided by the government and donors to provide support, in particular to individuals with AIDS. In addition to nutritional support, the councils made provisions to cover housing, clothing and medical expenses. They also ensured the deployment of nurses to carry out HBC activities. Furthermore, the *wereda* AIDS councils operated, in collaboration with *kebele* administrations, *idir* societies and youth associations, to carry out information, education and communication (IEC) programs.

At the time of the study, grassroots organizations, such as *idirs*, were especially prominent in the field of care and support services. Besides their involvement in the provision of socioeconomic and material support, they played a large role in community sensitization and educational campaigns relating to HIV/AIDS. These organizations were trusted and accepted by the community. Other agencies had recognized the

influence these organizations exerted amongst community members and were using this influence to their advantage, especially to promote their own respective HIV/AIDS services. It was particularly interesting that these CBOs were beginning to adopt innovative approaches to respond to the exigencies of the prevailing circumstances. For example, some had been flexible enough to accommodate amendments to their organizational policies regarding the timing and manner of cash payments to members in need.

Problems encountered by PLWHA as they tried to access different forms of existing care and support services were also investigated. In general, clients observed that the services were inadequate and duplicated; a lack of coordination seriously affected the activities of the service providers. A further shortcoming emphasized by clients was the lack of clarity and transparency as to which types of services were provided by each agency. From the viewpoint of PLWHA, lack of access to this information was hindering straightforward and effective utilization of the existing continuum of care and support services. Moreover, a failure to assess and prioritize the actual felt needs of recipients was also mentioned as one of the constraints, which seriously limited benefits of the existing services.

Participants also mentioned that they faced attitudinal problems when trying to access care and support services. In general, the attitudes of community members to HIV/AIDS and PLWHA were discouraging and harmful. PLWHA feared being identified as HIV positive. Accordingly, many stayed away from support systems, thereby depriving themselves of the benefits available to them. There was a strong tendency for communities to associate the provision of benefits with HIV/AIDS. Surprisingly, professional care and support staff as well as immediate family members were cited amongst the community groups who unfavorably linked acceptance of assistance and supplies with HIV infection. Such trends had increased the level of prejudice faced by PLWHA, resulting in their social isolation and actual discrimination.

In some places, shortages/lack of availability of drugs for treating opportunistic infections contributed to the unsatisfactory nature of the support systems. Moreover, in situations where the required medicines were available, the drugs were often too

expensive for many of those who needed them. Furthermore, poor quality care and low levels of attention from medical personnel were further aggravating the limited access to the existing health service networks. Despite the importance of VCT, several deficiencies were observed in VCT services. There was inadequate public knowledge about this aspect of the continuum of HIV/AIDS care and support services. Existing diagnostic facilities often failed to meet the desired standards and capacities for testing, making it difficult for the service to meet the needs of volunteers for VCT. In addition, although help was expected from VCT counselors, it was not always forthcoming to the extent that one would hope for and desire. Participants commented that various factors, such as inadequate training and limited numbers of counselors, were interfering with the quality and quantity of counseling that volunteers for VCT could expect to receive.

Beyond identifying the constraints and challenges faced by PLWHA, practical ways of addressing these problems were examined, from the participants' standpoint. It was felt that if the government gave due policy attention to PLWHA it would help to bring about meaningful changes in current care and support practices. Participants also felt strongly that the available provisions and programs needed reconsideration in light of the actual felt needs of the recipients. Furthermore, FGD members expressed strong feelings that the involvement of PLWHA in efforts to deal with the problem could not be overemphasized. The role of PLWHA in policymaking, needs assessments and project planning and implementation was felt to be a key element. Nevertheless, it was recognized that an effective care and support system would not be possible without the introduction of a realistic monitoring and evaluation system. Accordingly, activities aimed at restructuring the continuum of HIV/AIDS care and support will need to include monitoring and evaluation activities.

It was recognized that a vigorous IEC campaign was crucially important in enhancing the quality of care and support provided. This could be achieved by tailoring educational programs to appeal to and suit the circumstances of different community groups. In this respect, it was believed that the involvement of various CBOs (such as *idirs*, religious groups and PLWHA associations) would facilitate attainment of the campaign's goals.

PLWHA underscored the relevance and efficacy of their active involvement in care and support services, primarily in HBC and the educational aspects of an IEC campaign. Although they accepted that trained personnel were capable of providing HBC, they maintained that their shared sentiments would allow them to identify better with bed-ridden HIV/AIDS sufferers. In comparison with trained personnel, they felt that they were in a better position to accomplish successful HBC-related activities including emotional support and counseling. In relation to educational campaigns, PLWHA felt that their serostatus enabled them to be particularly productive in community sensitization against HIV/AIDS through discussion of their own situation and public teaching. In addition, PLWHA pointed out their needs for adequate training in HBC and counseling, and access to antiretroviral therapies. They said that guarantee of these opportunities for them would facilitate their meaningful involvement in HIV/AIDS interventions.

Finally, participants considered media habits and sources of information relating to HIV/AIDS. Radio and TV programs provided the largest bulk of information on HIV/AIDS to the average person. In addition, the more literate section of the community obtained in-depth updates on the issue from reading printed materials and by attending educational forums, such as seminars.

Despite the undeniable informative power of the various media channels, participants mentioned reservations and outright rejections of the way many messages were delivered. In particular, they criticized the language employed in communicating the educational messages. This language had been chosen to alert audiences to the dangers of HIV/AIDS and motivate them to take appropriate precautions; however, community members of different backgrounds objected that the messages sometimes missed their intended purposes and in fact might even produce negative results. Overall, the wording and phraseology characterizing some media messages on HIV/AIDS were described as unpleasant, incomprehensible to the lay audience, unnecessarily explicit, highly suggestive and culturally insensitive. PLWHA also complained that besides being unintentionally harsh on their feelings, IEC media programming largely dwelt on HIV/AIDS prevention rather than care and support for those living with HIV/AIDS.

Recommendations derived from the findings of this study include the following:

- There is a need to build the capacity of PLWHA groups so that they become less dependent on instructive players in the response to AIDS.
- Behavior change communication (BCC) and other interventions to destigmatize HIV/AIDS need to be intensified both amongst the general population and medical professionals; moreover, language used in the media should respect these efforts.
- To ensure that the rights of PLWHA, AIDS orphans and vulnerable children can be protected, the policy and legal framework needs strengthening.
- Traditionally, CBOs developed because community members saw the need to mobilize themselves to address burial needs. To meet the demand for HIV/AIDS care and support services and strengthen community-based responses, efforts should improve to mobilize engagement of the CBOs.
- VCT is an entry point to HIV/AIDS prevention, care and support and should be made more widely available while ensuring quality of the service and links to other services, including antiretroviral therapy at an affordable price.

1. INTRODUCTION

1.1 Background to the study

Ethiopia has the second largest population in sub-Saharan Africa. Although the HIV/AIDS epidemic has occurred long after similar epidemics have affected many East African countries, it is expected to have major negative effects on socioeconomic development in Ethiopia, a country already considered one of the five poorest in the world.

According to sentinel surveillance data, the Ethiopian Ministry of Health (MoH) estimates that in 2001 the national adult HIV prevalence in Ethiopia was 6.6%; however, in urban areas adult prevalence was estimated to be much higher (13.7% across all urban areas of Ethiopia and 15.6% in Addis Ababa) (MoH 2002). Presently, in Ethiopia, it is estimated that about 2.2 million adults and children are infected with HIV; this figure includes around 200,000 HIV infections amongst children (MoH 2002).

Antenatal sentinel data from seven regions of Ethiopia indicate that the prevalence of HIV infection amongst pregnant women in urban populations ranges from 3.1% in Ginir (Oromia) to 23.4% in Bahir Dar, Amhara region (MoH 2002).

In Ethiopia, the history of war, and internal and external displacement of families/children cannot be ignored when designing and discussing the well being of children and the impact of HIV. Government estimates indicate that, in 2001, there were 1.2 million children who had been orphaned as a result of AIDS; this number is expected to increase to 2.5 million by 2014 (MoH 2002). In the '*Children on the brink*' report (USAID, UNICEF and UNAIDS 2002) the total number of orphans in Ethiopia in 2001 was estimated to be just over 3.8 million of which 25.8% were orphaned due to AIDS.

In addition to the AIDS orphans, many other children are in vulnerable situations because of HIV/AIDS; these children may be facing worse conditions than some AIDS

orphans. With one or more parent ill from the disease and unable to provide the necessary economic and psychosocial support, many children may be denied their right to health care and education. Children may be forced to work to earn income for the family or be subjected to various forms of exploitation, including sexual exploitation. At present, very few government services exist to help HIV infected parents to plan for the welfare of their children after their deaths.

In addition to the other burdens of disease, people living with HIV/AIDS (PLWHA) are subjected to stigmatization and fear; this contributes to the culture of silence surrounding the disease and consequently to its spread. Moreover, socio-cultural obstacles (misconceptions and taboos) also contribute to the silence surrounding AIDS and eventually its spread.

According to ILO (1984), AIDS is an example of an illness of stigma. A stigma is any characteristics that set an individual or group apart from the majority of the population with the result that the individual or group is treated with suspicion or hostility. It has also been reported that social stigma and people's reactions to the person infected can be more deadly than the disease itself. Stigma also reinforces an air of desperate denial.

According to a report by the Society for the Advancement of Human Rights Education (SAHRE 2002), PLWHA and their associates face denial of access to employment, education, health services, social benefits, care and support, and information. They also face expulsion from home and community, refusal of requests to rent houses, notification without confidentiality, uninformed testing, ostracism, harassment, physical violence and moral condemnation by families, friends, community members and some religious groups (SAHRE 2002).

AIDS-induced stigma, as all others, can be painful and devastating. Discrimination and social stigma weaken the social relations that once existed between HIV infected individuals or families and their neighbors. In time, social and family disorganization can result due to a gradual breakdown in the overall social fabric.

At present, of all the world's countries, Ethiopia has the 16th highest HIV/AIDS prevalence level; moreover, because of Ethiopia's large population, it is estimated that one out of every eleven persons living with HIV/AIDS worldwide is an Ethiopian (NAC 2001).

Up to the year 2000, the cumulative number of deaths from the epidemic in Ethiopia is estimated to be as high as 1.2 million (MoH 2000). This figure is projected to increase to 1.7 million by the end of 2002 and to 5.2 million by the end of 2014 (MoH 2000).

Within the capital city, Addis Ababa, the picture is similar. The epidemic is claiming the lives of the most productive, energetic and educated segments of the population. The cumulative number of deaths resulting from HIV/AIDS in Addis Ababa was estimated to be 53,000 in 1999 and is projected to be 554,000 by 2014 (AACAHB 1999).

Prevalence of HIV is highest amongst the adult and youth sectors of the population; approximately 16.8% of these sectors is affected. At present, it is estimated that 286,000 adults and 12,000 children living in Addis Ababa are infected with HIV. Moreover, these numbers are increasing as each day nearly 100 people in Addis Ababa are contracting HIV. In Addis Ababa, the number of children orphaned as a result of AIDS was estimated at 20,000 and 30,000, respectively, by the Addis Ababa City Administration Health Bureau (AACAHB 1999) and the Organization for Social Service for AIDS (OSSA 2000). Given current trends, the number of AIDS orphans is likely to continue to increase. Accordingly, it is projected that numbers of AIDS orphans will increase to 64,000 in 2002 and to 145,000 in 2014 (AACAHB 1999; OSSA 2000).

Appalling as the current HIV/AIDS-related data are, they are unlikely to represent the full scale of the devastation and misery that will result from the HIV/AIDS epidemic in Ethiopia. Millions of people are already infected with HIV and the rate of new infections is increasing. Consequently, increasingly large numbers of people are at risk of contracting HIV in the coming years. Left unchecked the consequences of the HIV/AIDS epidemic in terms of human distress, and effects on the national economy and future generations are likely to be colossal.

In response to this realization, the incumbent government has recently developed policies and strategies to contain the spread and impact of HIV. The National AIDS Council (NAC) has been established to coordinate on-going multi-sectoral HIV/AIDS projects in Ethiopia. Currently, the NAC operates in accordance with a five-year (2001-2005) policy document entitled the 'Strategic framework for national response to HIV/AIDS in Ethiopia'. To date, Ethiopia's response to the situation has concentrated primarily on the prevention of new infections through advocacy, information, education and communication (IEC), and behavioral change communication (BCC). Presently, however, there is increasing focus on the provision of care and support services to PLWHA and other individuals affected indirectly by HIV/AIDS. This approach is highlighted in the strategic framework, which states that there is a major focus on the alleviation of 'the personal and social impact of HIV/AIDS by ensuring comprehensive care and support to PLWHA and reduction of the social and economic impact of HIV/AIDS on their families' (NAC 2001).

It is difficult to estimate the number of people who need HIV/AIDS care and support services in Addis Ababa. In addition to the increasing number of HIV infected individuals, some form of care and support is also required by many others who are affected indirectly by HIV/AIDS including AIDS orphans and elderly people who have lost supporting family members to the epidemic.

It is vitally important to appreciate and understand the needs of PLWHA from their own perspective. Such knowledge and information play crucial roles in the design and implementation of workable care and support systems.

Throughout the world but particularly in what is termed as the 'Third World', much human suffering is caused or aggravated by social forces and social forces should be studied by medical anthropologists. Suffering is a legitimate subject of ethnographic investigations, with important intellectual and ethical provisos. One of these provisos is that the 'lived experience' of the disorder is paramount (Farmer 1992).

Studies show, that in less developed parts of the world, the needs of PLWHA tend to originate in their means of survival. Aggravated by the diverse impact of the illness, the livelihoods of those affected decline ever deeper into a state of destitution. Accordingly,

in such a situation, care and support needs of PLWHA include access to health care, empathy from health staff and the community, financial assistance for daily necessities, and some security for survivors. A new concept has evolved from the lessons learned through different care and support studies conducted in various socioeconomic settings across the world. This concept is referred to as ‘comprehensive care across a continuum’. The concept involves the major components of clinical care, psychological support (counseling), socioeconomic support, and support for human and legal rights of people affected by HIV/AIDS.

Little systematic information, if any, is available on HIV/AIDS care and support services in Addis Ababa. Consequently, it is difficult to answer questions such as: what type of care and support services exist in the city; what are the needs of PLWHA and their families; and what challenges do PLWHA face in accessing the existing care and support networks? Nevertheless, in the fight against the HIV epidemic, the practical value of answers to these questions is clear. Predominantly, the answers to these questions would facilitate the provision of affordable, effective and holistic care and support services to PLWHA and their families. Therefore, primarily, this study was conducted to assess HIV/AIDS care and support services in Addis Ababa on the basis of information from five selected *weredas* in the city.

1.2 Specific objectives

1. To identify existing care and support services in Addis Ababa;
2. To determine the problems encountered by beneficiaries in the process of accessing these services;
3. To identify the needs of PLWHA from their own perspective;
4. To gain an understanding of the attitudes of the community towards PLWHA and of the perceptions of PLWHA towards the community; and
5. To gather suggestions from community members and PLWHA on how best to improve the current care and support services.

2. METHODS

The study was carried out in five *weredas* of Addis Ababa, namely *weredas* 5, 7, 15, 19 and 20. These *weredas* were included because HIV/AIDS care and support activities had been implemented in these *weredas* for over a year through the EMSAP (Ethiopia Multi-Sectoral AIDS Project). Two qualitative methodologies were employed for data collection, namely, focus group discussions (FGDs) and individual in-depth interviews with key informants. Seven FGDs were carried out. Five of these included community members drawn from the five selected *weredas*; one FGD was undertaken with each of the following groups: *idir* and religious leaders, female *idir* leaders, teachers, the youth and *wereda* HIV/AIDS council members. The other two focus groups constituted representatives of PLWHA; participants came from two associations for PLWHA, namely, Mekdim Ethiopia and Dawn of Hope. Individual in-depth interviews were carried out with 21 PLWHA; these individuals were representatives from each of the five study *weredas*.

FGDs were conducted on issues pertaining to the needs of PLWHA and their families. The main purpose of the FGDs was to identify and determine the type and extent of the needs of PLWHA. Moreover, a further objective was to assess the perceptions of PLWHA of existing HIV/AIDS care and support services, including any problems encountered in the process of accessing these services. FGD participants were also asked what they thought should be done to improve the quality of current HIV/AIDS care and support services. Furthermore, they were asked about sources of HIV/AIDS information, education and communication (IEC) and their views of its content.

3. DISCUSSION AND PRESENTATION OF FIELD DATA

3.1 Needs of people living with HIV/AIDS (PLWHA) and their families

On the basis of the FGDs held with representatives of PLWHA and community members, the needs of PLWHA were classified broadly into the following four categories: emotional and psychological, physical, socioeconomic and health care.

During FGDs, both male and female PLWHA revealed a strong desire for social acceptance and sympathy as one of their utmost needs. They described a strong internal urge to acquire the affection and concern of others. They said such love and attention would strengthen their sense of security and enable them to withstand the stress caused by their circumstances. They mentioned that isolation by the community exerted detrimental effects on them, as well as on their children and other family members. Social stigma deprived them of social worth, motivation and the will to live, in addition to aggravating the individual's health conditions.

The need for social acceptance and sympathy at all levels, from family to government, emerged as a recurring element in the course of all FGDs. Particular emphasis was given to the failure of the government in this respect. A participant in the female FGD made the following point, 'I have not heard the Prime Minister, being the most senior government official in the country, speaking about the needs and circumstances of PLWHA.' The respondents perceived this to illustrate the lack of attention given to PLWHA by the government.

Another concept raised during FGDs was that fighting the HIV epidemic should be viewed as waging a great war, the like of which the nation has never experienced. Accordingly, another female participant made the following striking comment, 'HIV/AIDS cannot be dealt with by force of arms as in the case of the war of Bademe.

This is a case whereby a single individual with the virus may be able to inflict casualties on a dozen others,' she continued.

The woman's comment was reinforced in a discussion session with the *wereda* HIV/AIDS council. The following is one of the numerous touching remarks made at the time:

If a government is to exist, there have to be people. At the moment HIV/AIDS is killing off the energetic and educated classes of the population at an alarming rate. The damage and losses inflicted are far more disastrous than what happens in conventional warfare. Huge as it is, the problem has not been given the policy attention that it deserves. In fact, the issue is never treated with the same degree of urgency and weight as certain politically sensitive matters. Hence, the problem will continue to cause a tremendous threat to the survival of the nation, until and unless the law-making and executive bodies address it, as they should.

The government needs to appreciate the gravity of the consequences. It is of utmost urgency that the government designs and implements policies geared towards ensuring the necessary attention and empathy for PLWHA. Community education relating to acceptance of PLWHA and campaigns to destigmatize HIV/AIDS need to be adopted as high priority measures by the concerned government bodies. Any effort towards achieving this focus needs to be viewed as a part of the overall struggle to deal with the epidemic, as well as being a response to one of the unmet needs of PLWHA.

Physical needs were identified as the second major requirement of PLWHA. These physical needs included provisions such as nutritional supplements, sufficient clothing and decent housing. Nutritional support figures prominently in this category. The focus groups perceived that the majority of people in question belonged to the poorer classes and therefore could not afford the diet they needed to cope with their circumstances. It has been proven medically that the amount and quality of nutrition a person can afford has a direct bearing on his or her longevity and capacity to withstand the debilitating effects of HIV.

However, nutritional support for PLWHA is more complex than the mere supply of adequate and regular provisions. FGD participants pointed out that current dietary provisions are inconsistent and minimal. In addition, current nutritional provisions,

which are mainly in the form of wheat, cooking oil, *teff* and *fafa* rations, may not represent the felt nutritional needs of the recipients. Moreover and more importantly, the community tends to associate the provisions with PLWHA, further aggravating the stigmatization and the resulting psychological trauma. Consequently, the primary needs highlighted by PLWHA included a reassessment of current nutritional support both in relation to the mode of administration and the beneficiaries' needs for its components. Furthermore, FGD participants commented that the coverage of nutritional provisions, currently limited to those infected with HIV, should be expanded to include the children of PLWHA, as well as other family members.

Finding permanent and decent housing at reasonable rent is the next largest material need highlighted by the groups. It is likely that pressures experienced by PLWHA as they rent houses from private owners or occupants and share services with their neighbors compound this problem. As even family members may isolate their close relatives who are living with HIV, the need of PLWHA for shelter becomes increasingly crucial. A common sentiment reflected by almost all participants is that, 'A roof over the head is something a person has to have, having spent a full day wherever he or she may.'

Countless examples were given by FGD participants to illustrate the severity of the mistreatment meted out to PLWHA in relation to housing. One of the many such cases, highlighted in the discussion with *idir* leaders, was as follows:

There is so much talk of care and support for PLWHA. However, once the head of the household becomes bed-ridden, the *kebele* administration starts unofficial negotiation to transfer the rented house to another occupant. Soon after the death of the patient, the transfer is forcibly carried out. This results in homeless for the children and immediate family members of the deceased. Thus, those affected indirectly by HIV/AIDS are subjected to a situation that increases their vulnerability to HIV infection, besides many other social ills.

In relation to the physical needs of PLWHA, concern for the future of their children was also brought to the fore. Many participants said that some of their children knew that they were infected and were coping with the virus. The responsibility of having to take care of themselves and their junior siblings weighed heavily on these children as they

awaited the imminent deaths of their parents. Most of the children did not have training that qualified them for any gainful employment. Thus, if young boys and girls in this situation were provided with vocational and job-oriented training before their parents' deaths, they would be better equipped to endure and survive the hardships they will face as orphans.

Health care services were the third category of needs prioritized by PLWHA. Health services included the provision of medicines for the treatment of opportunistic infections, as well as professional counseling and psychological support to help mitigate the impact of the stress resulting from HIV infection. As part of the medical services, home-based nursing and treatment were emphasized as a need of those PLWHA who were confined to bed.

A comment by one HIV-infected participant summed up the multiple needs of the group:

Prior to contracting the virus, we did not have different needs than those of the general community. Then we used to work and support ourselves as any other members of the society. Now, though, our circumstance has changed. We desperately need clinical care, professional support, food and nutrition as well as the love and empathy of the community. If these needs of ours are met, we will for our part do everything we can in the campaign to save the present generation.

3.2 Existing HIV/AIDS care and support services

Role of associations of PLWHA

Responses of male and female participants living with HIV showed that Dawn of Hope and Mekdim Ethiopia rendered the largest proportions of HIV/AIDS care and support services. These were the only two associations of PLWHA operating in Ethiopia at the time of the study.

Provision of professional HIV/AIDS counseling was pointed out as the most important care and support service. Almost all beneficiaries agreed that they consistently received group and individual counseling from these associations. They felt that such

professional services enabled them to cope successfully with the pressures of both HIV infection and the social stigma associated with it. In addition to members of the associations, AIDS orphans and vulnerable children benefited from the counseling services. A considerable number of beneficiaries expressed strong views attributing their ability to survive to this particular type of service. They said the psychological comfort that came from the professional counseling support gave them the moral strength to face the challenges of their circumstances. The beneficiaries added that counseling had enabled them to live longer and also to feel better and stay healthier.

Counseling provided by Dawn of Hope was considered to be so good that one participant commented, 'It does literally alter your life.' Some participants mentioned that HIV counseling, such as that offered by Dawn of Hope and others, should not be a once-in-a-life time experience, as is currently often the case. They suggested that the service should be provided more frequently.

On the other hand, some participants mentioned negative experiences in relation to counseling services. One participant made the following comment, 'I will never, ever forget what a nurse told me when she was informing me about my serostatus for the first time. This is what she said, 'Use condoms so that you might be able to live up to five years.' The other problem was that she made me visit the center frequently just to obtain my blood test result.'

A second major type of care and support services constituted various forms of socioeconomic provision. Members reported that the associations regularly provided them with food, including rations of edible oils. Each month, they were also given 100 Ethiopian birr (ETB; US\$ 1 = ETB 8.5 in July 2002) per head to cover part of their living expenses. In addition, association members on medical treatment were provided with up to ETB 400, on a case-by-case basis, to buy medicines prescribed by physicians. In times of bereavement, members of the association were also entitled to a sum of up to 50 Ethiopian birr to provide the funds needed to host visitors.

Orphan care and support was the third major type of service offered by associations for PLWHA. Before providing this service, the associations first investigated whether an

orphan had lost one or both parents as a result of AIDS. Once they had established that AIDS was the cause of orphanhood, they enrolled the child as an association member. Subsequently, group counseling and discussion were used to assess the felt needs of the orphans. The following services were available to eligible orphans:

- *For HIV infected orphans:* nutritional support, house rent and medical care were provided;
- *For orphans needing in-house care:* nurses were hired to cook their food and do their cleaning. At the time of the study, Dawn of Hope was caring for 20 AIDS orphans through hired nurses and guardians at a group home organized for this purpose;
- *For school age orphans:* supplies of educational materials and school uniforms were provided twice a year;
- *For orphans who tested HIV negative:* adoptions were arranged with interested volunteers, local or foreign. In this effort, Dawn of Hope had made adoption arrangements in the USA for a number of such orphans; and
- On public holidays: arrangements were made for major holidays, such as Christmas, Easter, New Years Day and Id ul-Fitr (the Muslim festival marking the end of Ramadan), so that the orphans could celebrate these events as the rest of the community do. With funds raised from different sources, special foods were served and some cash provisions were made to assist the beneficiaries.

A fourth major type of care and support service mentioned was legal support. When members and AIDS orphans became victims of abuse because of their HIV status, the associations provided them with support. The associations fought on behalf of the victims to protect their safety, and rights with the police and in a court of law. It was often their role to ensure that abuse cases were tried justly so that any damage caused was duly redressed and proper punishment was meted out to perpetrators.

A fifth major type of care and support service provided by the associations for PLWHA was home-based care (HBC). This care was provided for PLWHA who were bed-ridden because of AIDS and for HIV infected children; trained home care agents, including individuals with and without the virus, provided this care. In the case of home agents who were HIV infected, the service offered a two-fold advantage. In addition to creating jobs, it provided an opportunity for HIV infected individuals to extend love and care to others who needed the same type of support as they did. The following thoughts, expressed by an individual with first-hand experience, sum up the effect of the work when accomplished with the desired motive and spirit:

Providing home-based care satisfies us the most. Personally cleaning up the individuals in need of care empowers them psychologically, in addition to the wholesome effects it has on their physical condition. They generally tend to develop a sense of group identity with those with the problem. When they get better and feel healthy enough to do some work, they present themselves to provide service as home-based care agents.

Community members in the focus groups were also asked about the existing care and support services for PLWHA. In general, their answers indicated that they knew about similar types of care and support services to those identified by PLWHA. Community members, however, focused on care and support providers other than the associations for PLWHA. Community members identified organizations involved in the provision of HIV/AIDS care and support as non-governmental organizations (NGOs), governmental organizations, community-based organizations (CBOs), youth associations and anti-AIDS clubs.

Role of NGOs

Community members mentioned voluntary counseling and testing (VCT) services provided by NGOs working on HIV/AIDS as one of the major forms of care and support services. Mary Joy Aid Through Development, Medical Missionaries of Mary (MMM) Counseling and Social Service Center, Hiwot Tesfa, Organization for Social Services for AIDS (OSSA) and CARE Ethiopia were singled out by community members as organizations that provided this particular service. These organizations offered VCT to

adults for a nominal sum of ETB 10 while services were free of charge for orphans and vulnerable children.

Moreover, these NGOs were also involved in the provision of material support such as food and cooking oil rations, clothing and cash donations. The same organizations also provided orphans and vulnerable children with support in the form of educational materials, school uniforms and cash to pay school fees.

Role of *wereda* HIV/AIDS councils

The government bodies involved actively in care and support services were the *wereda* HIV/AIDS councils; each operated closely with its respective *wereda* administration. These *wereda*-based organizations were responsible for coordination of the community-based response. With funds from the government and international donors, the councils funded CBOs so that they could provide their beneficiaries with nutritional support, clothing, and cash for house rent and school fees. The councils also provided financial support to bed-ridden AIDS patients. Moreover, they paid for VCT services for orphans and covered the orphans' additional needs. In addition, it was mentioned that during public holidays, the councils organized committees to visit AIDS orphans and provide them with comfort, food and other necessities.

The other major care and support activity supported by the *wereda* AIDS councils was home-based care (HBC). In one case, the council hired nurses and ensured that AIDS patients and orphans were given home-based care. In relation to this type of support, female *idir* leaders mentioned the active involvement of a local NGO called Pro-Pride. In cooperation with the *wereda* HIV/AIDS council, Pro-Pride provided training to HBC agents. In another case, a *wereda* HIV/AIDS council was reported to liaise with potential adopters, both inside and outside of Ethiopia, to facilitate sustainable care for AIDS orphans.

Wereda 5 HIV/AIDS Council, for example, had secured adoption pledges for 15 beneficiaries aged between one and five years old. The council corroborated its care and support activities with sustained information, education and communication (IEC) campaigns. In collaboration with *kebele* administrations and *idir* leaders, the *wereda*

AIDS council supported HIV/AIDS awareness programs conducted by professionals for *wereda* residents at public places and assembly halls. Informative messages were also communicated to community members in the neighborhood by means of loud speakers.

Role of youth associations and anti-AIDS clubs

Youth associations and anti-AIDS clubs, operating within the *wereda* at the *kebele* level, were among the CBOs actively involved in the dissemination of IEC. They provided peer education in cooperation with anti-AIDS school clubs on various HIV/AIDS related subjects. As the major media for IEC, these clubs used different entertaining and creative activities such as drama, poetry, music and other forms of the literary arts. Furthermore, a particular focus area for the clubs was the promotion and distribution of condoms, and provision of information on condom use. Their major venues for this type of campaign were streets, recreation centers and schools. In addition to these activities, from time to time, the youth associations and anti-AIDS clubs staged candle-lit vigils and rallies to highlight the seriousness of the problem. They used the occasions as additional forums for the promotion of public awareness regarding HIV/AIDS. As part of their care and support services, the clubs collected donations of food and used clothing from residents of Ethiopia and hotels to distribute to PLWHA and AIDS orphans; such distributions were mainly made on public holidays.

Role of *idir* societies

Idirs, community burial and support associations, had important roles in HIV/AIDS care and support, and IEC. FGDs amongst both PLWHA and community members identified these grassroots institutions as key players in various areas of the response to HIV/AIDS. In some cases, *idirs* were involved in care and support service provision to AIDS patients and orphans, and in distribution of food rations and clothing to beneficiaries. Items provided by the *idirs* to AIDS orphans and vulnerable children included educational materials and school uniforms. These supplies were funded by small contributions collected from *idir* members.

The severity of the HIV/AIDS problem seemed to have prompted readjustment of the community outlook and approach with regard to support for those affected. In relation to

this, Praag (2000) wrote, ‘The needs of PLWAs [PLWHA] are only being partially met by formal health social services, but communities have generated innovative responses to cope with the increased number of patients and to improve the quality of life of PLWAs.’

In connection with this, a recent policy shift amongst an increasing number of *idir* societies was a change in the timing and manner of cash payments. Traditionally, *idir* societies had made cash payments for an eligible member to his/her surviving family only upon the person’s death. At the time of the study, however, in view of the severe pressures that PLWHA experienced, postponement of payments until after the member had died was being perceived as unreasonable. Accordingly, one participant in the *idir* focus group criticized the traditional support procedures adopted by the *idir* societies. The *idir* chairperson pointed out that the institution usually withheld offers of practical care and support to suffering members. When the individual died, the money, which could have been used to care for him/her, was paid to surviving family members, so that they could use it to pay for funeral costs including hospitality (e.g. food and drink) to visiting comforters. The *idir* chairperson presented several examples illustrating the intensity of the problem and the impact it was making on the perceptions and modus operandi of the *idir* societies.

The first case described by the chairperson of the *idir* FGD, involved an *idir* member with HIV/AIDS who submitted an application to the committee. Part of it read, ‘I am in extreme agony. I badly need your support. Get me what I desire while I am still alive. I need the money now, which will be paid upon my death anyway. If I should recuperate and leave bed, I will pay it back in installments. If death should ever take me, the amount will be deducted from what is due to be paid out then.’ The *idir* leader said the committee’s reaction to this petition was an emotional outburst of grief and tears. Nevertheless, he added, ‘We were not able to change long-standing norms and practices at that point.’ The request was refused.

The *idir* chairperson continued, mentioning that a similar letter was soon received from another member with the same problem. The second letter read, ‘My work contract is

over and I am now out of job. I have run out of money to buy my food and pay house rent. My body craves meat and butter. My family members no longer want to care for me. I am against my due share of the support money from the *idir* being given over at my death to a family who has neglected me. So buy me what I desire to get now.’ The *idir* chairperson added, ‘This time, we started to sense the truth that rings in such expressions. We changed our attitudes and reconsidered the appeal. Thus, we provided the patient with what he asked for.’

On the basis of such considerations, the *idir* society had to revise its constitution so that suffering members could be cared for with the support money they were entitled to. In addition, the constitution was amended so that financial help of up to ETB 1000 was available to procure necessary medicines and to subsidize the purchase of foods to build the resistance of infected individuals.

Idir societies were also active in the area of IEC relating to HIV/AIDS. They carried out awareness activities amongst their members, in collaboration with NGOs and anti-AIDS clubs at school and at the *kebele* level.

Problems encountered in accessing HIV/AIDS services

FGDs with PLWHA revealed that each individual was benefiting, in some way, from the care and support services mentioned previously. Most HIV infected participants, felt that they benefited most from material support and counseling services. They said that these services were not restricted to members of the associations for PLWHA. In fact, the majority of beneficiaries for these services were not affiliated with the associations for PLWHA. In relation to counseling, all participants spoke about group discussions and counseling sessions organized for them every week by an NGO called Hiwot Tesfa. During discussions and coffee parties, participants freely discussed sensitive individual and group experiences that they encountered in their day-to-day lives. They were open and positive about the consoling and therapeutic effects of such discussions.

Other care and support services mentioned by the beneficiaries were medical services and HBC. When individuals registered at health centers for the treatment of any

opportunistic infections, their medical expenses were taken care of by organizations such as Hiwot Tesfa and OSSA. The participants mentioned that HBC services were increasing constantly. In addition to receiving care themselves, the beneficiaries stated that they took part in training so that they could provide HBC services to others. In particular, the HBC services provided by associations for PLWHA were highlighted.

A major problem singled out by participants was the practice of withholding services from individuals who were already receiving support from a different provider. This practice was an issue for beneficiaries, even though they realized the rationale that made providers reluctant to serve those who already had some access to a support system. Often, care and support agencies argued that they had difficulties in obtaining enough supplies/funding to distribute. Agencies seemed to believe that they could circumvent the problem by serving only those individuals who had not been served before; thus, limiting the number of beneficiaries. Nevertheless, recipients strongly contended such reasoning by pointing out the circumstances of many support-seekers and the lack of coordination amongst the support systems. Commenting on this, participants living with HIV/AIDS (males and females) were single-minded. They remarked that support services rendered by government agencies and others were inadequate, minimal and short-lived. They pointed out that their HIV/AIDS status forced them to become heavily dependent on what they could procure from the care and support networks. Moreover, currently, provisions available at distribution centers were barely enough for the recipients and those under their care.

Supplies were not only inadequate but they also lacked variety; for example, supplies often consisted of only one type of food, such as wheat, teff, barley, or cooking oil. When beneficiaries received this one type of food from an agency, they subsequently found that they were refused other supplies from a different agency. This approach was widespread despite the fact that it is not possible to meet nutritional requirements from a single type of distributed food. The need for rations with a high nutritional value is extremely important in the case of PLWHA, especially as adequate nutritional support can delay the onset of AIDS.

PLWHA expressed their preference for a diverse support program, which they indicated had a more practical value. Beneficiaries suggested that the support program would benefit from better donor coordination and follow-up, particularly with respect to the continuity, variety and amount of provisions available. They implied that they needed lesser quantities of different items rather than too much of a single item. They proposed that support institutions should adopt an approach where each of them focused on a single type of support; for example, one of them should focus on beneficiary needs for a particular form of nutritional supply while another should deal with financial requirements.

Women living with HIV/AIDS pointed out that their objectives were not merely to reap benefits for themselves but also to assist in the fight against the spread of the virus.

Speaking on this point, one of the women expressed her ideas as follows:

I have lost my husband and my job. So, I have only the support system to rely on for my survival and that of my children. True, I look well and people cannot tell whether I am living with the virus or not. In general, men can get attracted to me because of my physical appearance. I can sometimes find it difficult to resist temptations, not out of negligence but out of the need to feed my little ones and myself. However, if the available provisions are such that I have no real wants as an infected person, I will do my best to abstain. Rather, I will feel duty bound to protect the men trying to make sexual advances to me.

Another woman described one of her experiences:

One day, I was invited to a marriage party held at the Crown Hotel at Kaliti, here in Addis Ababa. I went out of the hotel to take a taxi back home before the party was over. It was already dark. I saw a man squeezing people into a nice four-wheel drive car. He also offered me a ride. I accepted the offer outright. I sat in the front seat upon the request of the driver of the car. The moment I went into the car he greeted me. I said, 'I am sorry I don't know you.' 'No problem, let us introduce ourselves to each other right now', he replied. 'My name is ... and I am an active member of Dawn of Hope', I opened up the introduction. He was shocked, bewildered, bemused and suddenly he stopped the car. Bereft of speech, after a brief deep thinking mood, he said, 'My sister God bless you! You know I have a hostess wife and I am a father of four. You saved me from a catastrophe.' Then he gave me ETB 50 and his phone number, and requested me to give him a ring. Finally, we said goodbye to each other. I never gave him a ring and never saw him afterwards.

Community representatives in the FGDs shared the view that there was inadequate coordination between NGOs working on HIV/AIDS. Consequently, there was duplication of programs and several agencies were concentrating their efforts on particular segments of the population while neglecting others. For example, the elderly, and to some degree the youth affected by HIV/AIDS, were failing to receive the attention that they duly deserved.

A related problem expressed by participants was the absence of accurate information about HIV/AIDS related activities provided by the various NGOs. The community and beneficiaries had no access to information concerning service coverage, focus areas and type of care and support activities provided by NGOs.

A major problem mentioned was the attitudes of beneficiaries and community members towards the HIV/AIDS related services. Because of stigma and discrimination, many PLWHA tended to avoid coming forward to ask for services; individuals did not want to be identified as PLWHA or to be associated with HIV/AIDS. The pressure was so intense that some individuals chose to remain silent about their serostatus, thereby avoiding the risk of being recognized by the community as being PLWHA. Similarly, AIDS orphans often decided not to register for care and support services because they felt that they had to come out openly in public; some rejected the services outright whilst others accepted the services anonymously. Public concern surrounding VCT, illustrated the general attitude towards HIV/AIDS care and support services. Participants indicated that most people preferred VCT to be provided as an integral part of general clinical services at health institutions. It was felt that individuals who sought VCT were more likely to visit integrated health centers than centers dedicated to VCT alone. By visiting integrated health centers, they did not need to publicly reveal their need for some type of HIV/AIDS oriented service.

Women's *idir* representatives mentioned a strong tendency to relate all support to bed-ridden patients to HIV/AIDS. One of the women recalled a serious argument between two men that brought the men before the *kebele* administration. The argument occurred because one of the men remarked that the wife of the other had died because of AIDS.

The man apparently attributed the services the widower received from the *kebele* administration to the serostatus of his deceased wife.

Another major problem cited by participants was that individuals needed to present an HIV/AIDS certificate before they could gain access to support services. This requirement seemed to prevent a considerable number of otherwise eligible recipients from accessing the support system. It seemed that individuals preferred anonymity to the expected stigmatization that might accompany processing of the required certificate.

A women's *idir* leader, added that rumors were also damaging their efforts to care for AIDS orphans and vulnerable children. She commented that these children often faced immense psychological pressure because the community labeled them as PLWHA. The children complained about people in the neighborhood who were gossiping or saying to them directly that they were supported because they had lost their parents to HIV/AIDS. The orphans and children knew that such talk presented them in a negative way to the public, leading to inevitable social isolation and ostracism. Unsurprisingly, in a great many cases, their response was to decline support services, and to say falsely that they were fine and in no need of special attention. Recognition of this situation had forced certain support providers, including *kebele* administrations, to take a different approach to AIDS orphans and vulnerable children. Some support givers were trying to persuade the children to accept their services by giving excuses to counter the children's objections. For example, some were telling the children that they were being offered support because they were in need rather than because of HIV/AIDS. There were reports that children who had been supported for a time under this pretext had withdrawn from support programs following the spread of rumors that support was provided because of HIV/AIDS.

Participants, particularly those living with HIV/AIDS, commented that in some cases access to care and support services was obstructed further by the attitudes of some care providers. Negative attitudes prevailed at all levels of care and support provision, from the attitudes of family members to NGO workers and professionals specializing in HIV/AIDS care and support. A male participant with HIV stated that he received a bag

of wheat from a distribution center but did not take it home. He explained that, ‘My family members do not know I am living with the virus. If they do, I know what their reaction will be. My anticipation is that they will reject me. Hence, I sell away the grain at a cheap price rather than sharing it with my family.’

The previously mentioned example shows that, even within the family group, attitudinal problems were hindering the proper use of supplies. PLWHA were not confident that their own families would support them if they knew of their serostatus. Attitudinal problems towards HIV/AIDS were revealed clearly by the fact that PLWHA were unable to confide even in their closest relatives. Thus, PLWHA were compelled not only to live with the virus but also to completely conceal their problems, even amongst their families. Such attitudinal problems at the family level were preventing PLWHA from making the best possible use of existing care and support services.

Attitudes to PLWHA amongst the *kebele* administrations were often even more frustrating. A male participant in the FGD for PLWHA commented that, ‘People at different levels of the city administration may prove to be unsympathetic or even hostile when personally requested for cooperation.’ He continued, ‘I once submitted a letter of cooperation from an association for PLWHA to an official. The letter requested support, on behalf of myself and another individual with the same status, in the form of *kebele* rented housing. However, upon figuring out from the title of the subject, the man did not care to read through the content. Looking up and taking a few glances, the man said “I wish you are not going to ask me for money.” When realizing what we were up to, he in the end had us move into abandoned latrine rooms now reused as dwellings.’

Moreover, *kebele* administrations were accused of corrupt practices perpetrated against AIDS orphans and vulnerable children. When parents died of HIV/AIDS their orphaned children had, on a number of occasions, been made to leave their houses so that other people could use the houses. In order to promote the selfish interests of some individuals, the orphans were denied the support they were entitled to. Members of the *kebele* administrations allegedly negotiated bribes from those wanting to rent *kebele* houses rather than working to ensure the safety and security of the AIDS orphans.

Problems relating to adoption of AIDS orphans were voiced during the discussions. One problem given major emphasis was related to the completion of adoptions on legally valid grounds. Many adoptions that were not carried out in accordance with strict legal procedures were reported to work to the disadvantage, rather than the benefit, of the parents and adoptees. Moreover, strong objections were expressed to the use of adoption as the primary solution for dealing with the children of PLWHA. Participants felt that it was best if families stayed together for as long as circumstances allowed. The rapid transfer of AIDS orphans into the care of adopters or orphanages was seen as encouraging family disintegration and eventually becoming counter productive. Another related problem was the lack of follow up on AIDS orphans once adopted. Examples were given of situations where financial and material assistance had been handed over to relatives caring for AIDS orphans but instead of this being used to provide care it was misused by the children's guardians. Given these undesirable practices, participants strongly suggested that adoption of AIDS orphans should be viewed as a last resort, used with all necessary precautions.

Even in places where beneficiaries were supposed to receive the best of care, attitudinal problems were encountered amongst service providers. These problems were manifested in different forms. Some service providers mistreated beneficiaries visiting health institutions for clinical care; the mistreatment faced by the beneficiaries included snubs, scolds and outright insults. In other cases, health workers pointed out that they were fed up with PLWHA and denied them proper care and treatment. Moreover, some health workers demanded greater proof of serostatus than that provided by official certificates.

Some NGOs engaged in HIV/AIDS related interventions also had poor attitudes towards PLWHA. A group of females living with HIV/AIDS reported that they collected monthly allowances at OSSA; on collection of their allowances, they were apparently asked to sign using pens that were only for use by PLWHA. Furthermore, the gestures with which financial support was administered sometimes lacked the sympathy and humanity that the recipients deserved. The allowances paid were not fixed and predictable but varied between months, for example, from ETB 50 to 70. Beneficiaries commented that organizations failed to appreciate that they deserved to be informed of

how much and when they should expect payments. Moreover, the general attitudes of providers were far from those that would make beneficiaries feel welcome and feel that they were in the right place. According to the beneficiaries, the providers gave the impression that the allowances were handouts after all; moreover, the providers seemed to indicate that they didn't care whether beneficiaries took or left their allowances.

Beneficiaries commented that OSSA staff often refused to render their usual services if the beneficiaries failed to show up on the date of their appointment. Worse still, it was reported that staff in the Finance Department of OSSA often covered their mouths with garments when talking to beneficiaries. Moreover, some OSSA staff members were reported to prohibit PLWHA from using their toilets. Most staff, ranging from guards to the managers of HIV/AIDS care and support organizations, were accused of lacking respect for PLWHA. Nevertheless, some of the staff responded well to PLWHA; they helped individuals to reach health centers and a few were kind enough to wash clothing for PLWHA. Other staff of care and support organizations reportedly had very poor attitudes to PLWHA; the staff covered their mouths with garment and did not want to be close to PLWHA. Beneficiaries felt that good professional staff were those who gave much of their time to advise PLWHA.

Male participants living with HIV/AIDS strongly criticized a local NGO called Mary Joy Aid Through Development. The men felt that this NGO abused their needs and circumstances to promote its own cause. They provided two examples to support their claims against the organization; both examples were intended to explain that Mary Joy was primarily concerned with its public image and the gain of publicity when making announcements of planned HIV/AIDS services.

In the first case, the organization widely advertised free VCT for those with lower incomes and low cost VCT (minimum cost of ETB 25) for the youth. However, it transpired that when daily laborers, housemaids etc attended for VCT services, the official letters they produced, regarding their social status, were rejected as invalid. Most were turned away without services or sufficient explanations. For example, when a woman living with HIV appealed for support, she was told to return with her three

children. When she returned with her children, they were videoed for a television program. After the program had appeared on TV, the woman returned to the NGO for support but was told that she needed further evidence that the children were really her own. Thus, she left the NGO without getting the services that the TV program had indicated she was already receiving.

The second case, involved a circus show staged by the NGO; this show was advertised and hundreds of youths in the neighborhood attended. Video pictures were taken of the young people attending the circus show; subsequently, these were used by the NGO as material for a TV program. It was perceived that the program falsely implied all those attending the circus to be beneficiaries of its services.

In addition, members of the Dawn of Hope Association accused it of being shortsighted and lacking in long-term perspective and/or vision for the betterment of the lives of its members. This problem was discussed in relation to the considerable deficit in housing, particularly for PLWHA because of stigma.

Participants in all FGD mentioned shortages of medicines as another major problem faced in accessing services. Beneficiaries emphasized that important medicines were in short supply at government health institutions but were available at higher prices at privately owned medical establishments. A great many PLWHA were unable to obtain crucial treatment since they could not afford to use the privately owned medical centers.

Informants suggested that income level was correlated directly with the quality of medical care received. They felt this was true, 'In that if you can't buy your medical care then you cannot seek treatment whenever and wherever you want to; likewise, you cannot buy whatever medicine you want to.' In short, low incomes were seen as being associated with limited access to medical services, poor quality of care and lower quality of attention from medical professionals.

One informant infected by HIV said:

My low level of income has a direct negative impact on the quality of services I obtain. In the first place, the fact that I live with HIV has affected my morale and

state of mind. I could not get married and have my own family; I could not travel abroad, work and live there. I cannot work for long hours in tough working conditions. Above all, it made me think and believe that people don't have positive opinions about me.

In particular, many PLWHA argue that the quality of medical care they receive is affected by the fact that the medical services are provided free of charge. The following quotations support this assertion.

First, an individual said, 'The fact that I am a pensioner with a very low level of income made me unable to buy the medicine I want; I could not eat the food I want, etc.'

Secondly, it was said that, 'When some medical professionals in hospitals realize that you are someone who is receiving treatment free of charge, they don't respect and treat you like those who are paying for their treatment. When you are HIV positive, people consider you as hopeless and they don't think that you deserve any attention and help. If you are a nonpaying health care seeker then you don't get the attention you deserve. The moment the nurses know that you are HIV positive and you are not paying for your treatment, then they get fed up of treating you as a patient.'

In principle, PLWHA have continuous access to government run health services. In practice, however, they can only use such services on weekdays, as they cannot produce letters of support from *kebele* administrations at the weekends. Moreover, the fact that pharmacies only accepted prescriptions from government run medical institutions was perceived as a problem. It was not clear why private prescriptions were not accepted; informants wondered whether it was because some private clinics did not have government licenses. These items pondered by the informants reflected their dissatisfaction with the existing government institution confined service provision arrangements for PLWHA.

A further but related problem was that PLWHA were expected to receive medical treatment from health institutions located in their own zone of residence. It was felt that this rule was restricting PLWHA's access to other institutions, perceived as providing a higher quality of service.

VCT services were also mentioned as an area where there were problems relating to access. The services were not readily available to all those wanting to undergo VCT. Moreover, amongst those individuals examined and found to be HIV positive, some found the counseling services less satisfactory than they had been led to believe when encouraged to take the test. In addition, some VCT counselors were far less competent than expected. Beneficiaries also commented on the insufficient quality and quantity of facilities at VCT centers. In consequence, many people were failing to access VCT services and occasionally some of those tested were receiving the wrong results.

The teachers' focus group pointed out that access to VCT services was sometimes restricted. For example, in certain neighborhoods, VCT services were only available to commercial sex workers; therefore, members of other community groups, who might want such assistance, were unable to access the services. A further problem identified was that the public was inadequately informed about the existence of VCT services. Although it forms an integral part of the continuum of HIV/AIDS care and support services, VCT did not seem to have received the attention it merits as part of the campaign addressing the HIV epidemic.

Suggestions for improvement of the HIV/AIDS care and support services

The role of the government

Women living with HIV/AIDS felt that the primary responsibility for ensuring PLWHA received appropriate care and support should lie with the government. At the time of the study, this task was largely being undertaken by NGOs, with only a small share being carried out by governmental bodies. One of the women noted:

Recently, a high level fund-raising program was organized for the Sendafa Athletics Village, with full government backing. Senior officials, public figures and private investors attended the event. One of the highlights was the auctioning of the picture of the late marathoner, Abebe Biqilla. The Saudi-based businessman, Sheih Al Amoudi, won the bid by paying half a million ETB for the portrait. What surprised us was that an event of a similar scale has not been staged for HIV/AIDS, portraying the smaller degree of attention given to the

problem. The irony, however, is that the future youngsters the nation hopes to cultivate in the athletics village will first need to be protected against the virus and the disease it causes.

The women's responses indicated their conviction that if the problem were treated with equal attention, a great deal would be accomplished in terms of containing the epidemic and saving a generation.

Attitudes and knowledge of care providers

Pertaining to the quality of care and support, a complaint was voiced by beneficiaries about insufficient training and a lack of commitment on the part of service-providers. Beneficiaries commented that since the concerned NGO staff greatly lacked knowledge and ethics, they tended to dismiss some service-seekers because of their outward appearance. For example, an unknowledgeable care-provider might make the following comment to a healthy looking beneficiary, 'You need no support or you come here only to make trouble.'

This concept was supported by comments from two other informants. The first commented, 'The fact that people's opinion about PLWHA is not good makes you feel uncomfortable to access the medical services you needed.' The second informant added, 'I am well dressed, well fed and good-looking; this has often made service providers think that I don't need any assistance at all. Yet, I feel inferior to others when I see depressed PLWHA waiting for help at Dawn of Hope.'

This mistreatment described by the informants revealed an absence of sympathy and professionalism on the part of some unqualified care and support staff. Informants added that often care and support service jobs were secured through a candidate's connections rather than as a result of the candidate's merits. Beneficiaries said, 'We hate being used as a means of self-promotion or give and take of favors.' They also mentioned similar experiences with supposed providers of clinical care. Moreover, they pointed out that there were clinic-based health educators whose knowledge was no better than that of the individuals they were assigned to educate.

The need for monitoring and evaluation

Male and female beneficiaries pinpointed lack of necessary follow-up as another major deficiency in the quality of service provision. They explained that there was no consistent effort by a responsible body, government or other group, to make sure that services and provisions had actually reached their targets. Furthermore, there was no ongoing evaluation and analysis of the impact of previous care and support activities, even though this was required to rectify mistakes and introduce necessary improvements. The need for a sound, workable monitoring and evaluation system was highlighted; this was required to oversee the way care and support services were conducted and to guarantee that the services reached and benefited their target groups.

HIV/AIDS information and education

All FGD participants emphasized the need for increased vigor in HIV/AIDS information and education. They agreed that campaigns should be more intensive and methodical. It was noted that sustained effort was required in the provision of HIV/AIDS information and education; moreover, a greater degree of objectivity and transparency was required in the process. Furthermore, equally importantly, the information and education program required greater focus; in particular, its approach and materials needed to be tailored to the needs of particular community groups.

FGD participants pointed out that the family unit deserves primary attention, as it represents the foundation of society. In fact, care and support to HIV infected individuals often starts at the family level. It was felt that women, particularly mothers, should be focused upon when providing education relating to the care of individuals with AIDS. This was justified with the rationale that care providers in the households were usually women. When husbands or children became victims of HIV/AIDS, it was natural for wives and mothers to become caregivers. Accordingly, by teaching mothers to care properly for those with AIDS, care would be provided for the entire household.

Other population groups proposed as targets for HIV/AIDS information and education included individuals who were unaffiliated with grassroots organizations e.g.

housemaids, daily laborers, the unemployed, and school leavers and drop outs. Like all community members, these groups were vulnerable to HIV/AIDS. Furthermore, they tended to miss out on information and education services because of their peripheral social status, particularly because it was difficult to communicate with them through the usual media channels.

The teachers' focus group suggested various concrete actions including the introduction of discussion clubs to provide sexual health education in organizations, factories and other establishments. It was also suggested that HIV/AIDS education could be provided to those attending health institutions for medical examination or treatment. It was felt that all HIV/AIDS education efforts would be successful if PLWHA were encouraged to participate actively as educators.

To implement information and education programs, it was deemed vitally important to use *idirs*. Most residents were directly or indirectly affiliated with an *idir*; this explains the vast potential the institution has in reaching and influencing wide cross sections of society. In contrast, FGD participants indicated the relatively low acceptability and authority of other organizations, such as *kebele* administrations, amongst people at the grassroots level. Hence, a shift of focus was suggested regarding the target groups for HIV/AIDS training and workshops; it was suggested that a deeper involvement by the *idir* leaders would greatly increase the capacity of *idirs* to contribute constructively to information and education campaigns. An *idir* chairperson made the following suggestion:

A significant number of *idir* members can be reached as they turn up to settle their monthly membership fees. These are convenient moments to screen relevant video films for members to watch. However, this can only be implemented if the *idir* can have access to a video player.

The potential role of religious leaders in HIV/AIDS information and education campaigns was also emphasized; as these individuals were already highly accepted and greatly respected by the public, their possible role was immense. Participants highlighted the success of Dawn of Hope who were already exploiting the potential of religious institutions in their HIV/AIDS campaigns. Furthermore, the role of 'father

confessors' was emphasized as having immense value. Traditionally, almost every family adhering to the Orthodox Christian faith had its own respective father confessor. These church figures were held in high esteem and could therefore use their special attachments to particular households as leverage. These leaders enjoyed the personal trust of the households that confided in them. Moreover, for families in their care, they were considered to be responsible for providing instruction, advice and censure in matters relating to sexual behavior. Consequently, it was recommended that vital information and education on HIV/AIDS should be communicated through father confessors at the household level.

It was suggested that religious institutions could also be highly influential in persuading community members to access VCT. Furthermore, participants felt that VCT would be encouraged if the services were provided at a reduced or token cost. A female FGD participant gave an example to support this suggestion. She pointed out that in *Wereda* 5, huge number of volunteers had turned up following the announcement of free VCT services. This example indicates that with sufficient sensitization and increased access to the service, the community would react favorably to VCT programs.

A leader of a women's *idir* proposed a radical approach to the transmission of pertinent HIV/AIDS information and education. She spoke of the necessity to challenge the lingering tradition of silence and secrecy about a problem that has 'been around for years and continues to knock on the doors' of the entire population. The woman considered that there was no better time and opportunity to teach the subject than at the gatherings of mourners in attendance at a burial. It was felt that open admission of HIV/AIDS as the cause of death would signify a break with tradition. Moreover, the situation would provide an opportunity to sensitize the public with regard to the lethal effects of HIV/AIDS and how close it is to everyone. It was, however, noted that this approach was likely to elicit undesirable reactions from bereaved relatives and the rest of the audience. Nevertheless, eventually, it was felt that long-held irrational views were bound to vanish as the general public increasingly gained awareness. Additionally, it was felt that repetition of the practice on burial occasions was likely to counteract the negative impressions the practice might initially make.

A further recommendation was the strengthening and expansion of the peer education strategy, already used by some organizations. Participants in FGD felt that messages would be appreciated more when the information was given and received by equals e.g. from woman to woman, or adult to adult. In such a setting, mutual understanding and shared experience should facilitate openness and the flow of ideas; moreover, the participants should feel unhindered about what they say and learn.

Another key proposal was that there should be greater involvement of PLWHA in organizations providing HIV/AIDS care and support services. There were two major justifications for this approach. First, it was felt that care-providers living through the same experience as the beneficiaries would show special sympathies to their fellows. Secondly, it was felt that to some extent, the active involvement of directly concerned parties in the care and support system might help in its monitoring and evaluation. Most participants in FGDs felt that the active presence of PLWHA would contribute to a sound control mechanism in relation to the proper management of resources, generated on their behalf. Discussion of the possible involvement of PLWHA in care and support services linked into discussion of the group's role in HIV/AIDS intervention activities.

3.3 Role of PLWHA in HIV/AIDS interventions

FGD participants living with the virus were asked if they had taken part in any HIV/AIDS intervention activities. Most affirmed their active participation in the provision of HBC. They said they were involved in HBC activities coordinated by associations for PLWHA and by NGOs with this program component. Major elements of the service they rendered included home visits, nursing care, palliative care, delivery of food supplies, emotional and spiritual support, and counseling.

Some individuals who admitted publicly that they were living with AIDS mentioned the part they played in information and education. Ex-soldiers made it known that they had agreed to be videoed as they engaged in public teaching. Furthermore, they had consented to the display of the video films at army camps across the country, including military bases where they had worked and were still recognized. Others expressed their

role in informal peer education; these individuals informed their acquaintances and companions about the reality of the problem.

When PLWHA were asked about the intervention activities they could meaningfully be involved in, all showed a keen interest in accepting any assignment, as long as conditions were made favorable for them. Nevertheless, they made particular reference to the following specific activities: HBC; counseling and psychological support; VCT sensitization; teaching publicly through self-exposure and the sharing of personal experiences; involvement in community mobilization for support of the collective anti-AIDS effort; and the provision of professional care as the employees of service institutions.

When asked what challenges they would expect to face if involved in intervention activities, PLWHA mentioned the following major concerns: family and social isolation manifested in various forms and to various degrees; and the likelihood that people might not take the information seriously because some educators looked healthy and had no visible signs of the virus.

When asked what they needed to increase their involvement in intervention activities, PLWHA emphasized two key social and professional requirements. First, they referred to the vital importance of community acceptance, in terms of understanding as well as expressions of affection and concern. Secondly, they highlighted the current crowded conditions in hospitals that mostly resulted from large numbers of AIDS patients. They pointed out that qualified HBC was the best alternative to hospital care for the provision of services to bed-ridden AIDS sufferers. They emphasized that PLWHA needed proper training in HBC and counseling to enable them to provide better services to these individuals.

PLWHA considered that it was important that life-prolonging antiretrovirals were introduced. It was felt that access to such therapies would reinvigorate a person's hopes for a longer and more productive life. It was thought that PLWHA who were treated with antiretrovirals would feel encouraged participate actively in as many areas of HIV/AIDS intervention as possible. Furthermore, it was felt that provision of

antiretrovirals would encourage those who had previously remained silent to discuss their serostatus publicly and to contribute their share in the public effort to fight the epidemic.

3.4 Attitudes of community members and health providers towards PLWHA

AIDS-based stigma manifests itself in a wide range of social contexts. Discussion of the attitudes of community members and health providers towards PLWHA aimed to reveal specific cases and contexts that demonstrated the discrimination and social stigma suffered by PLWHA and AIDS orphans. In order to better understand the magnitude of the problem, it was necessary to consider stigma in a case-by-case context.

Within the family-

Stigma relating to HIV/AIDS was often so pervasive that even the family unit was affected. One of the women living with HIV/AIDS gave the following emotionally charged account. She started by saying that her husband was handsome and was ill with HIV/AIDS for five years. The woman continued by explaining that her mother-in-law kept insisting that she was told what was wrong with her son. The woman said:

I, however, would not disclose the disease for fear of the fact that people would be scared away. One day, though, the mother demanded that I tell her the cause of her son's illness. I asked her to leave my husband and me alone so that I could change his clothes. I wanted the mother to walk away so that she would not see the sores on the skin of my husband as I undressed him. But the mother would not let me do that in private. At that, I told her it was HIV/AIDS. Once the mother knew that the disease could not be cured, she began praying an early death to her son. I objected to this telling her that despite his present condition, he was still my husband and I wanted him to live. From then on the mother kept distance from my husband and did not lay hands on him. Only in the presence of visitors did she pretend to care, feeling around him under the cover of his blanket.

The woman concluded by saying that HIV/AIDS creates such serious stigma that it can even separate a mother from her son.

An *idir* leader also shared his own experience of how serious the stigma of HIV/AIDS could be within the family. He told of a rich merchant whose son was ill with HIV/AIDS. The son lived in the merchant's house but all his family, including his brothers and sisters, refused to attend to him. The father approached the *idir* leader and asked him for someone who could nurse his ill son, offering to pay well for the service. The *idir* leader said that he was disappointed by the attitude of the father and replied, 'If you, being the father, hate to take care of your own son, who else will offer to do the job for you.'

A female FGD participant who was infected with HIV related the following personal experience:

My brother who lives in Germany came over to visit after a long period. However, when he heard that I had publicly announced myself as living with HIV/AIDS virus and was giving community education about the epidemic, he kept his distance. Never did he show up to see me, let alone give me any money. He even took back the gift he had brought for me and returned to Germany in that state.

Another female living with the virus related the following first-hand experience:

My family is not aware of my being HIV positive and a member of Dawn of Hope, an association for PLWHA. My brother, who had gone to Gode for work, returned ill within a month. He was almost unconscious when I received him and immediately took him to a hospital for a test. He was announced HIV positive. My sister who is a practicing nurse did not show interest to care for him once she knew of his disease. I did my best to nurse him covering myself with gloves but this did not make my sister change her attitude. She told our mother about it [his HIV status] and she also deprived him of her maternal love and care. As a result, my brother died shortly afterwards.

Another female informant commented on her own experience as follows:

When I first heard about my serostatus, I informed my parents about it. They easily accepted it and they used to care and advise me to eat nutritious food. They tried their best to make me happy and not to be depressed because of the death of my husband. Then I joined the Dawn of Hope Association. Soon after that my family members considered me like '*ar yenekaw inchet aderegugn*' [literally 'A stick with feces sticking with it']. All members of my family isolated me but luckily I made non-kinsmen kinsmen [and they] frequently visit and encourage me.

Lastly, a young male informant related his story. He said, 'I have never been isolated from the community and did not experience such a thing. You know why? [Because] my relatives and friends do not know that I am HIV positive. The day these people know my serostatus, I am certainly sure that I will have to face such grim circumstances of discrimination and the problems associated with it.' The interviewer asked, 'How?' 'One day we [my friends and me] were chitchatting about HIV AIDS. They were of the opinion that it is not proper for a person who lives with the virus to eat and drink with other people because that person can infect these people in a way that he/she is not aware of. From this I realized that the moment my friends knew my serostatus they would isolate me.'

Within the work place-

The work place was another social context where HIV/AIDS-induced stigma had major effects. A woman living with HIV/AIDS related the following story, which illustrates stigma in the work place. The woman started by explaining that her husband was a cook at the Hilton International Hotel in Addis Ababa:

As painful rashes on his skin persisted, he went to the Hilton clinic for treatment. An HIV/AIDS test was recommended for him. He tested positive. Upon learning of the test result, the management suspended him from his job. Within months of his suspension, he applied to be reassigned to a different job, like timekeeping or gardening. The management declined his petitions. Worse still, I also lost my temporary employment at the hotel only because of being his wife. As a result, he took to heavy drinking, which eventually led him to the loss of sanity. Things deteriorated so rapidly that he finally left home, withdrew all his savings from the bank and squandered it all on drinks. He ended up yelling around at the pubs that he was HIV/AIDS positive. At last, he committed suicide. Many people said, as I do myself, that the immediate cause for my husband's painful death and the resulting family breakdown lies with the management of the company where my husband and I both used to work.

At health institutions-

HIV/AIDS associated stigma is probably most perturbing when it occurs in situations where it is least expected. In this respect, the experiences of some participants living with HIV/AIDS indicated that even professionals and institutions supposed to provide the best care and support to those infected with HIV did not always behave according to

professional ethics. Informants described the following incidents that occurred as they attempted to access services at health institutions.

An HIV positive, female participant said:

One day, I went for medical treatment to Yekatit 12 Hospital, with a certificate issued to me by Dawn of Hope. As my husband waited outside, I confessed my serostatus to the physician and asked him for his help. The action of the physician was shocking to say the least. He knocked me against the wall and dragged me out of the room shouting, 'What can I do for you? This is a disease you brought on yourself while you sexually abused yourself'. Although my husband saw and heard this, he could not do anything for he was very ill himself.

A second female informant contended that:

Medical professionals at health institutions do not give you due respect when they realize that you are HIV positive. This is so because they know that it is a terminal illness. I had a problem with my ear. Seeking medical treatment, I went to Zewditu Hospital. I was referred to a specialist at Yekatit 12 Hospital. It took me two whole days to see the specialist. When I met the specialist, I told him that I live with the HIV virus. He said, 'You should have protected yourself from HIV/AIDS.' We [PLWHA] badly need love, I said. 'I know very well that that is your usual mantra', he replied. 'Death means nothing', he continued. When he was examining my ear, he was very careful not to touch it. It was like when you try to handle dirt with your hand.

The third female informant related the following story:

I visited a dental clinic where I revealed myself to the nurse on duty as HIV positive. She was the same person who treated me on an earlier occasion. Then, [previously] she treated me with proper attention having me choose the medical procedure I preferred. This time, though, she indirectly declined to perform a tooth extraction because I am HIV positive. Instead, she prescribed an expensive x-ray examination for me, although she knew I did not need and could not afford it.

The same informant had a similar experience with a different health service provider. 'I was once referred to Black Lion Hospital for a gynecological examination', she said. 'Upon reading my referral paper, which tells of my HIV/AIDS status, the physician ordered that I buy ten pairs of gloves.' Upset and surprised, she spoke up to the doctor, 'You need ten layers of gloves because I have the HIV virus?' She concluded by

commenting that, ‘Not even the educated in this country [Ethiopia] have made the appropriate changes in attitude and conduct.’

A man with the virus related an incident he had experienced at an NGO engaged in HIV/AIDS care and support. The episode involved a physician working for the NGO known as Pro-Pride. The man explained that:

Once, I confided to a nurse at this NGO about the problem I had with the virus. She referred me to a doctor there and told me to explain my medical history to him. As I broke to him the story of my infection with the virus, the physician could not stay where he was. I noticed him retreat in his chair in a state of shock and disbelief.

Finally, a woman participant described the following incident that occurred when she was receiving HBC services:

I was seriously ill [with *almaz balechira* (herpes zoster)] and getting visited by three women home-based caregivers. I grilled beef and offered it to them. One of the caregivers refused to eat. I inquired why. She said, ‘I saw you holding a knife so how do I know if you cut your hand.’ Besides, she was thirsty. I had to offer her water begged from my neighbor because she did not want to drink with my glass.

In contrast to the previously mentioned negative incidents experienced by individuals attempting to access medical care and HIV/AIDS related services, one informant commented on her positive experience. She said, ‘Yes, I am satisfied with the medical, psychological/moral and financial support my husband and I have been receiving from our association, Dawn of Hope, and Zeweditu Hospital. You know Dr Tekeste Kebede of Zeweditu Hospital is like the father of all of us [members of Dawn of Hope]. He cares for our health and our psychological make up.’ Likewise, two health professionals working for Bethezatha Medical Center were mentioned by informants because of the excellent care and respect they provided for PLWHA.

In residential neighborhoods and community organizations–

Other social settings in which the stigma attached to HIV/AIDS had major affects included house rental and interaction with CBOs. PLWHA experienced particular

difficulties when trying to find rented accommodation or when wanting to become members of CBOs.

A female FGD participant, who was an active member of an association for PLWHA, Mekdim Ethiopia, told her story as follows:

One day, I was at the Addis Ababa Stadium taking part in a routine public HIV/AIDS awareness campaign. When I got back home, my renters [landlords] had thrown all my belongings out of my dwelling. They likely learned of my serostatus from someone in the neighborhood or more probably from people in the *kebele* leadership. I informed the *wereda* police, who on arrival found the renters locking themselves up in their house. They refused to open their door and explain their action for a long while. They finally did so only upon police insistence. When the door opened, my little son jumped into their house, as he usually did. It was emotionally hard for me to bear seeing him pushed out by those with whom he previously felt safe and comfortable. Angered by what my renters did, I tried to remind them of how close we were before their knowledge of my HIV/AIDS infection. I asked, 'Have we not shared a table and broken bread together?' The householder answered, 'That is an old story and things are different now. Today, it is like I am seeing HIV/AIDS in flesh and blood.' By police arbitration, the rent was extended for me by three months. Nonetheless, I could not stay in the house that long. They [the landlords] did all they could to upset and frustrate me into going away. They dumped garbage and filthy water just close to my exit. On holidays, they also slaughtered animals and emptied the entrails right where I lived.

The woman went on to relate her experience in connection with her membership of a women's *idir* in the neighborhood.

I was on the leadership committee for the *idir*. Upon realizing my HIV/AIDS status and my role in Mekdim Ethiopia, fellow committee members began to subtly ostracize me. They stopped notifying me of committee and general meetings, as well as charging me membership contributions. Thus, by withdrawing all previous forms of social interaction, they dismembered me in the end.

A male focus group participant, who was infected with HIV, related another incident of social ostracism. He said:

I had to change rented houses three times in eight months. Each time, I was forced to leave under pressures from house owners and neighbors. When they somehow learned that I had the virus, they resorted to different tactics to socially isolate me. They deprived me of access to communal toilets, as well as

the telephone. As discrimination became unbearable at one place I had to move and seek shelter somewhere else; however, most of the time, that [finding alternative accommodation] proved equally difficult. On one occasion, I appealed to a *kebele* authority for help in prioritizing my request for housing. The *kebele* member said something to me that I did not anticipate; the comment embittered me all the more. He said, ‘Why should the *kebele* serve you first for a problem you caused yourself, while there are so many members of the defense force looking for housing?’

It was reported that the *kebele* administrations often disclosed the serostatus of PLWHA without their consent. When this happened it had many repercussions for the concerned individuals, in terms of their social standing and social relations with those they were close to.

At funeral services-

Social stigmatization of those with HIV/AIDS did not stop at the death of the individual. Often, it went beyond that, seriously affecting the funeral process of the deceased party. Almost invariably, participants of the FGD with *idir* leaders tended to make similar comments on this matter, for example, one participant said:

When an HIV/AIDS suspect dies, people generally show extreme disgust toward the body. They are scared because they feel that getting close to the body can expose them to the virus or the disease. Hence, it is not easy to arrange funerals since undertakers may not be willing to readily handle the body. Similarly, less *idir* members may be available to accompany the body in a funeral procession than at other funerals. Moreover, those who show up to pay their respects to the deceased do so out of fear of the fine imposed on those who fail to attend the ceremony.

A woman informant described one incident succinctly:

It happened in Merkato some time ago. There was a married couple that lived together for a long period of time. When people realized that the couple was HIV positive they stopped visiting them at all. Then the husband died. We [a group of HIV positive women] were informed about the death of this person. We showed up. We learnt that men refused to prepare the corpse for burial [*megenez*]. Men normally carried out this preparation. Nevertheless, we were forced to prepare the corpse and put it in a coffin. Then we invited men to come and join us in the burial. They totally refused to touch the coffin. We had to do almost everything by ourselves.

Idir leaders also highlighted the impact of stigma on the provision of care and support. For example, they explained that many AIDS orphans declined material support once they knew why the support was being given. The children dreaded being identified by the community as recipients of assistance for AIDS orphans. The children's fear of stigmatization was so strong that they preferred not to take the provisions. Those who choose to accept the support tried their best to receive it secretly, so that no one else knew. Reportedly, the beneficiaries wanted provisions to be delivered to their dwellings. They complained that they would be seen by community members as they visited or left distribution centers. Moreover, some HIV positive parents totally rejected any support because they didn't want their children, let alone anyone else, to know that they were infected. In certain cases, offers made to support AIDS orphans had met with violent protests. It was reported that some older children (boys and girls) had even threatened to start lawsuits for defamation against support providers; these children considered that by offering support, the providers were falsely attributing their parents' deaths to HIV/AIDS.

3.5 Attitudes to PLWHA in public services and other social settings

Participants described various manifestations of stigma and discrimination against PLWHA including: neighbors locking up shared *kebele* toilets; guests invited to a death commemoration feast refusing to eat and drink at the home of a PLWHA; and the abrupt decrease of love and affection from previously very close friends, as reflected by less visits and expected friendly contacts. Fear of isolation and the general negative stigma attached to HIV/AIDS were the major reasons why many PLWHA didn't want to disclose their serostatus to their very close friends and relatives. In addition to these social settings and circumstances, AIDS-based stigmas manifested themselves in a wide range of other social contexts, such as on public transport and at public gatherings. The following examples illustrate stigma and discrimination in some of these contexts.

A woman living with HIV related her story as follows:

I declared my serostatus in public via the mass media last year. One day, I was traveling by taxi. The taxi driver ordered me to sit at the very corner of the taxi seat. I refused to do so. I told him, 'Like others I am also paying you – not traveling free of charge'. 'You deserve not this car but the one meant for transporting a coffin with a corpse inside', he replied. I believe that this happened to me simply because I am a woman. If I were my husband it would not have happened to me.

An HIV positive male informant commented, 'I declared my serostatus in public. I taught people about HIV/AIDS in public. Accordingly some people isolated me. They use sign language to talk about me.'

A male Muslim informant contended that, 'I have never been discriminated against because nobody knows that I am an HIV positive person. I am not getting spiritual and moral support from anyone either. This is because I did not tell anyone that I live with the virus.'

Participants were asked what action they thought should be taken to deal with stigmatization and discrimination. Women living with HIV proposed the urgent importation of life-prolonging drugs (antiretrovirals) because HIV/AIDS-induced stigma was directly associated with the lack of a cure or treatment for the disease. Most PLWHA were discouraged from publicly announcing themselves because HIV/AIDS was known as an untreatable disease. Without a change in this way of thinking, it was felt unlikely that more HIV positive individuals would come out to declare themselves. Accordingly, it was felt that the prevailing fear and apprehension surrounding HIV/AIDS would be reduced by increased public awareness that antiretroviral drugs could prolong the life of PLWHA. Furthermore, it was felt that if PLWHA knew that treatment might be accessible it would rekindle their hopes for survival. In addition, it was believed that ongoing education of the public, to give them an accurate picture of what the virus is and what can be done despite it, would contribute greatly towards the reduction of stigma.

The HIV positive women cited examples from Uganda and Kenya as proof for their argument. In these countries, the availability of antiretroviral treatment had brought about profound changes, unimaginable only years before. The women mentioned that in

Kenya and Uganda, HIV positive individuals had become so open about their HIV status that some were even serving at restaurants and cafés with stickers on their uniforms stating, 'I am HIV positive'. The reason behind this degree of transparency and public acceptance of HIV was the understanding that the virus could be treated. Participants felt that introduction of antiretrovirals would increase public acceptance of HIV.

Participants felt that the Government of Ethiopia should heed the appeals to adopt the same measures. They recognized that ways and means needed to be sought to procure the medicines through loans, aid or other channels. Moreover, it was felt that organizations working in the area of HIV/AIDS care and support needed to redouble their efforts to this end.

3.6 Media habits and sources of information on HIV/AIDS

PLWHA, and community and religious leaders discussed various aspects of HIV/AIDS information, education, and communication (IEC). First, they were asked how they obtained information about HIV/AIDS. Both discussion groups highlighted their dependence on radio and TV for information about the virus. The two forms of media played a major role in the dissemination of information, particularly because societal levels of literacy and reading habits were unsatisfactory for printed media to have sufficient impact. Nevertheless, participating teachers and *wereda* HIV/AIDS council members pointed out that printed fliers, workshops, campaigns by anti-AIDS clubs and publications such as the *Tobia* magazine provided additional valuable sources of information.

Amongst relevant radio programs, the FM-Addis radio show '*Yibekal*' was singled out as a source of HIV/AIDS information, particularly by women living with the virus; this program, sponsored by a local [indigenous] NGO called Pro-Pride, was presented three evenings/week. A number of participants mentioned that they had come into contact with associations for PLWHA, Dawn of Hope or Mekdim Ethiopia, by way of this radio program.

Notably, religious leaders of both Islamic and Christian faiths referred to the number of deaths from HIV-related causes as their major source of evidence for the extent of the problem. They estimated that in previous years, their respective cemeteries dealt with no more than two HIV/AIDS-related deaths/week. At the time of the study, they reported that this figure had increased to about nine deaths/day, reinforcing the accuracy of what they were hearing about the scale of threat presented by HIV/AIDS.

Representatives of women's *idirs* said that they were informed about the nature and impact of HIV by PLWHA who had actively taken part in various anti-HIV/AIDS campaigns. Teachers participating in the FGDs also confirmed that the first-hand experiences of PLWHA were a major source of their information about HIV/AIDS.

Participants in the youth focus group appreciated the radio drama, sponsored by Pro-Pride that was presented on Sundays on FM-Addis. Moreover, youths from the Merkato area highlighted the informative value of fliers prepared and distributed jointly by Pro-Pride and the Birhan Integrated Community Development Organization. In addition, they said that the Addis Ketema Neighborhood Newspaper, produced with sponsorship from Pro-Pride, was amongst their most important sources of information and education on HIV/AIDS. The youth also valued eye-catching and informative posters and stickers displayed at various strategic locations and visibly worn by people. DKT-Ethiopia, an NGO working on HIV/AIDS, was also reported to sponsor the production of reading materials that were used at *idir* meetings. Teachers and students cited these channels of IEC to be highly beneficial and educative.

Results indicate that educated members of the community, such as teachers and students, benefited from printed media such as fliers, posters and newspaper articles. However, community groups with little formal education, such as senior citizens, were inclined to rely on audiovisual forms of communication (i.e. the radio and TV). The single, most important medium providing HIV/AIDS information in Addis Ababa was radio; almost all FGD participants mentioned radio. Its relative affordability to community members of different income levels had made radio the most accessible source of information. The nature of radio programs and the considerable amount of

airtime given had contributed to the popularity of FM-Addis as a source of HIV/AIDS information. These characteristics enabled FM-Addis to reach a wide and diverse audience (including housewives, domestic servants, shop keepers and taxi drivers) whose circumstances allowed them to listen to the radio while doing their jobs.

Secondly, participants were asked to evaluate the quality and content of the information they had obtained. Some participants mentioned that the time allocated to HIV/AIDS was too short considering its importance. It was noted that on radio and TV, the time allocated to coverage of HIV/AIDS issues was far less than that devoted to business advertisements. Participants commented that HIV/AIDS features were brief and minimal; moreover, coverage was not constant, sometimes the features seemed to appear in rapid succession whilst at other times they appeared irregularly and only occasionally. Some participants sounded bitter when they said, 'The presenters seem as if they want to run [communicate] all they have about HIV/AIDS at one shot and get it over with'.

Furthermore, it was observed that media coverage of HIV/AIDS issues was limited in geographic terms. Although all the forms of mass media (TV, radio or press) were relatively accessible to urban communities, none were readily available to rural populations. Hence, it was felt that increased effort was required to disseminate HIV/AIDS information deep into the farming communities; different and more appropriate approaches were required. It was suggested that rural-based community organizations, such as peasants' associations, work parties and *idirs*, might have a valuable and practical role in the process of wider IEC dissemination. Even in urban centers where broadcasting and printed media are common, the functions performed by grassroots organizations have proved immensely helpful. Accordingly, in both urban and rural environments, exploitation of existing networks in a more organized and strengthened manner could undoubtedly support, if not replace, IEC campaigns through the regular media channels. Some participants developed these ideas further by commenting on the organizations they felt were best suited to disseminate IEC relating to HIV/AIDS; they felt that, in general, community members considered *idirs* more credible and closer to their needs than *kebele* administrations.

Evaluation of the language used in media HIV/AIDS materials strongly suggested the need for reassessment and the exercise of greater care. Participants often mentioned that the language used in HIV/AIDS campaigns was not appropriate/comprehensible to many of the targeted community groups. For example, a female participant reported that one of her relatives from the countryside had heard the HIV/AIDS introduction, 'Value your life', before a radio news bulletin. The female visitor reportedly asked her host 'Does the announcement mean that people should pay attention to the news?' Although the wording of these critical messages is intended for the 'average' audience, it is likely that the messages are incomprehensible or poorly appreciated by many of those who need such reminders.

A further point made in relation to HIV/AIDS media language, was appropriateness/suitability of the expressions used. From a cultural viewpoint, nearly all participants capitalized on the unacceptability and unpleasantness of at least some of the language used in media campaigns. In some cases, parents would not allow their children to view or listen to HIV/AIDS material because it was perceived to be sexually explicit and stimulating.

PLWHA criticized the media's HIV/AIDS messages for being unbalanced, misrepresentative, repetitive and giving the wrong impression. They felt that whatever information was communicated should take into account the feelings of those already infected. For example, an HIV positive woman expressed the following view:

When I hear the message 'Value your life', I feel hurt because the wording seems to convey the idea that I got the virus due to failing to value my life. But, if it was differently worded with our sentiments and emotions duly considered it would appeal to persons living with and without the virus.

She suggested, 'Let us care for those who live with HIV/AIDS' as a more effective, balanced and appealing message than 'Value your life'.

A general tendency by the media to represent PLWHA as looking thin and pale was identified as a flaw in the content of media coverage of HIV/AIDS issues. The repercussion of such media images could be far-reaching and disastrous. It was reported that association of HIV with solely physical manifestations had led to the mistaken

belief that as long as a person looks healthy, he/she lives without the virus or is safe from its effects.

Almost all FGD participants severely criticized IEC materials advocating condoms use. It was felt that under the pretext of HIV/AIDS prevention, present IEC materials advertising condoms sent home strong sexual signals to those of tender years and grown-ups alike. The thrust of such messages had often been perceived as promoting sex rather than abstinence. To illustrate this point, the following advertisement was quoted:

Mr X: Do you have a condom?

Mr Y: I certainly do!

Mr X: Stop by and enjoy then.

It was felt that this advertisement implied that the purpose of condoms was gratification rather than prevention. However, it was noted that the best protection that condoms offer only equates to that offered by a firefighter's shield in the face of a fiercely blazing fire. Women's *idir* representatives said, 'No matter how well they are dressed, firemen cannot be totally immune in a fire situation.'

Accordingly, FGD participants proposed that condom associated IEC should be designed to include transparency on the risk involved. Participants stressed that the condom should be viewed only as the last alternative after abstinence and staying faithful to one's partner. They stressed the seriousness of this aspect on the basis of their experiences and observations. The participants felt that the false confidence surrounding condom use, especially amongst adolescents and adults, was already backfiring. These individuals were visiting entertainment centers assuming a misplaced sense of security because they were in possession of a packet of condoms. In this frame of mind, they were drinking alcoholic beverages to the point of losing sobriety. Some were drinking too much to care about using condoms whilst others attempting to use condoms were too drunk to use them properly.

Participants in the teachers' FGD commented on conflicting information relating to condom use. Despite reports that up to 100,000 condoms were sold each day, there were indications that HIV/AIDS transmission rates were still increasing and the spread of the epidemic was continuing unabated. This presumably indicated that not all distributed condoms were utilized properly. Therefore, it was felt that the promotion of safe sex should include education about the proper use of condoms. Some participants also wondered about the monopoly held by a single brand of condom, Hiwot Trust, while several other types of condoms were known to exist.

In relation to the general coverage of IEC, it was suggested that consideration be given to certain sections of the community who, for various reasons, might not have been reached or targeted at all. Amongst other groups, daily laborers, housemaids and night students were cited as being at a disadvantage in respect of public awareness campaigns. Therefore, to ensure comprehensive and ultimately productive campaigns, it was felt that there was a need for IEC programs designed and implemented for these community groups.

4. RECOMMENDATIONS

This study focused on the perceptions of PLWHA and other targeted and selected community groups. Perceptions about existing HIV/AIDS care and support services, problems encountered in accessing the services, the priority needs of PLWHA and various related issues were examined. On the basis of the results, the following recommendations were made to assist in the review and improvement of the existing continuum of HIV/AIDS care and support services.

1. Human and other resources should be provided to enhance the capacity of associations for PLWHA. Increased and consistent support will empower these organizations to play a more coordinated and independent role in HIV/AIDS care and support services.
2. Efforts to destigmatize HIV/AIDS, including concerted and sustained behavioral change communication (BCC) activities, need to be intensified. A collective BCC program could improve social attitudes and practices towards PLWHA.
3. The requirements and problems of PLWHA and their families need to be addressed. For example, the issue should be incorporated into all relevant government policies.
4. Attitudes of care and support providers need to change from a notion of helping PLWHA to helping PLWHA to help themselves.
5. PLWHA, AIDS orphans and vulnerable children need legal protection. Specific legislation and policies are required to curb human rights abuses and discrimination against these groups.
6. To avoid duplicity of programs by enhancing the coordination of care and support activities. Moreover, the design and implementation of programs needs to be based on the expressed needs of the beneficiaries.

7. Community-based organizations (CBOs; e.g. *idirs*) should be empowered by providing technical, material and financial assistance. These grassroots institutions have the trust and acceptance of community members. Close collaboration with these CBOs will help to increase their engagement at various levels of the care and support network.
8. More effort should be made to popularize and increase voluntary counseling and testing (VCT) amongst the public. Although VCT has a crucial role in the care and support system, it has not yet received adequate attention. Much work is required to bring about sufficient attitudinal change, procure the necessary facilities and make available the qualified staff for expanded, high quality VCT services.
9. Systems should be devised, which ensure that an individual's serostatus is not disclosed without written consent from the individual himself/herself.
10. Medical staff and care and support workers should be trained so that they accept PLWHA as they are. This is a key element of successful service provision, particularly given the various dimensions of stigma attached to HIV/AIDS services.
11. A PLWHA-led, home- and community-based approach should be encouraged as the primary option for the care and support of AIDS orphans and vulnerable children. This and other studies have shown that orphans generally cope better in their own homes or communities. Therefore, adoption or institutional care for AIDS orphans and vulnerable children should be pursued only as a last resort.
12. Antiretroviral drugs need to be made available at the lowest possible prices. Besides the benefits to PLWHA, the availability of therapies will guarantee the eventual success and productivity of the entire care and support undertaking.
13. In HIV/AIDS publicity, language used by the media should be adapted so that it meets professional standards and is culturally acceptable. The media, particularly TV and radio, plays a powerful role in information dissemination and

communication about HIV/AIDS. A more prudent, acceptable and appealing use of language by media agencies will contribute to an effective IEC campaign.

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