HIV/AIDS in Addis Ababa: Understanding the Care and Support Needs and Problems of Young People Living with HIV/AIDS and of AIDS Orphans

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Introduction

It is common knowledge that the HIV/AIDS prevalence rate in Ethiopia is already one of the highest in the world. According to the latest statistics provided by the Disease Prevention and Control Department of the Ministry of Health (2002), 2,2 million persons (6.6 percent of the entire population) currently live with the HIV virus. Two hundred thousand of these HIV cases are reported to be children. The same source projects that the rate of prevalence will remain generally consistent until 2010. Accordingly, the prevalence rate will rise to 2.6 million in 2006 and 2,9 million in 2010, which figure involves both people living with the virus and full-blown AIDS cases.

The above study, with data drawn from 34 sentinel surveillance sites around the country, reported an average urban prevalence rate of 13.2 percent. The current prevalence rate for Addis Ababa is 15.6 percent, after five other urban centres of the 34 sentinel sites. The period from 1989 to 1995 marked a steep increase in HIV prevalence for Addis Ababa. However, a gradual decline in prevalence rates started in 1995 and continued to date. Given sustained prevention and control efforts, the projection for the coming years is that there will still be a further let up in the prevalence rate for the capital, with prospects of increased decline.

The study also furnishes a set of findings on age and sex specific rates of HIV prevalence for the country. Thus, it indicates the peak ages of AIDS cases to be 25 to 29 for both females and males. Taking into account eight years of the incubation period, on average, between infection and the emergence of the full-blown disease, the mean ages in which people get infected range from 15 to 24 for females, and 25 to 34 for males. According to available data, by far the largest numbers of people infected with HIV are concentrated in the age groups of 15 to 24, and slightly to a lesser extent, 25 to 34 for females. The age groups of 20 to 24 and 25 to 29 represent the highest rates of infections for males. The variations in the sex and age distribution of the HIV cases may be explained by early sexual activity among young girls and the fact that they often have older partners. The thrust of the findings is that prevalence and infection rates appear to be declining with age.

The evidence reinforces the implications of the current prevalence statistics that are obviously serious and far-reaching. Primarily and severely affected are the most energetic and productive segments of the population who bear the brunt of the epidemic. The theme 'Young People: Force for Change', chosen for the 1998 World AIDS Campaign, was no doubt prompted by the realisation and appreciation of these facts. The campaign brought to the fore the power of the young in the process of introducing and implementing changes. It emphasised that the future of the epidemic lies in their hands. The life styles that they adopt today can determine which course the epidemic is going to take over the years to come. Research has amply shown that the young will adopt safer sexual behaviour provided that they are given the necessary information, means and skills around HIV/AIDS prevention and control, including care and support for the infected and affected. Increased orphan-hood is a single major dimension of the impact exerted by HIV/AIDS. Men and women dying from HIV/AIDS-related causes in their prime child rearing ages often leave orphans behind them. In this context, an AIDS orphan is someone under 15 who has lost a mother to AIDS. However, given the important role heterosexual relations play in the transmission of the virus, a child is most likely to lose both parents to the disease although the deaths may occur at different time intervals. The recent study by the Disease Prevention and Control Department of the Ministry of Health (2002) projects that the number of AIDS orphans in Ethiopia, which was 1,2 million in 2001, will jump to 1,8 million in 2007 and to 2,5 million in 2014. The Addis Ababa City Government Health Bureau (AACGHB 2000) and the Organisation for Social Services for AIDS (OSSA, 2000) provide two different figures on AIDS orphans in the city. The former puts the number at 20,000 and the latter at 30,000 for the year 2000, during which year each organisation conducted the study. Both studies projected that the number would increase to 64,000 in 2004 and 145,000 in 2014 (AACGHB 2000; OSSA 2000).

The Ethiopian Government issued a national policy on HIV/AIDS in 1998. The policy aims to direct the various efforts put forth to mitigate the impact of the pandemic. To this end, two government bodies have been set up with different but complementary mandates and responsibilities. The government has vested in the Disease Prevention and Control Department (DPCD) of the Ministry of

Health (MoH) the responsibility for the planning and implementation of HIV/AIDS prevention and control programmes. It has also established an HIV/AIDS Prevention and Control Office (HAPCO), which is responsible for mobilising multi-sectoral and grass root efforts in the fight against the epidemic. The national policy on HIV/AIDS carries two broad components. It is geared towards the implementation of preventive programmes and the provision of rehabilitative services for the infected and affected. The care and support system lies at the heart of the rehabilitative component of the policy. In fact, one of the stated policy objectives relevant to this study runs in these words: 'Make the necessary provision of care and support to people living with HIV/AIDS and their affected family members'. Within this policy framework, this study endeavours to identify the felt care and support needs of young people living with HIV/AIDS (PLWHA) and AIDS orphans in Addis Ababa. In addition, it provides a profile of the care and support networks currently in place in the city, and the challenges that beneficiaries encounter in their attempt to access the services.

Research Objectives

This research aimed to achieve the following objectives:

(i) Ascertain the needs and problems of young people living with HIV/AIDS and AIDS orphans, from their own point of view;

(ii) Establish how these young people prioritise these needs and problems along gender lines, among other factors.

(ii) Evaluate the effectiveness of these networks in the light of the judgment and perception of beneficiaries.

(iv) Find out the challenges encountered in the process of accessing available care and support services.

(v) Obtain community feedback from selected research populations on the practical remedies towards the improvement and expansion of existing care support services.

Research Methods

The research methodologies employed involve four participatory techniques of qualitative data collection:

(i) Key informant interviews: Concerned and selected community members such as the elderly, community leaders, teachers, students, health workers, and leaders of youth associations and anti-AIDS clubs were interviewed with a view to drawing up a general community perspective on the most pertinent themes of the study. Major questions presented to key informants using this method had to do with the social impact of HIV/AIDS, stigma issues and social support systems.

(ii) Focus group discussions: Discussions were held with male and female burial associations (Iddir) leaders, Woreda (district) HIV/AIDS council members, and young people living with HIV/AIDS who are members of Dawn of Hope and Mekdim Ethiopia, Associations of PLWHA. The purpose of the discussions was to generate the required data on the needs and problems of the affected community members, and the services provided to address them.

(iii) Individual in-depth interviews: Young people living with HIV/AIDS (male and female) and AIDS orphans were interviewed on person-to-person basis, so that they would express their experiences with HIV/AIDS, recount the community reactions to their status, inform us of their coping mechanisms, as well as their concerns, hopes, and life styles.

(iv) Participant observation: This method was employed in a more restricted sense of the term, to gather information through an intensive face-to-face interaction with the subjects of the study. Participant observation tends to be a more active process than direct observation. It involves prolonged contact and frequent encounters, particularly with informants having 'specialised' knowledge about matters under investigation and who display the goodwill to share experiences with the investigator. The researcher pursued participant observation as an ideal method of personal involvement and interaction to make the best possible use of opportune social situations.

Description and Analysis of Field Data

Needs and Problems of Young PLWHA

In-depth interviews and focus group discussions took place separately with young males and females living with HIV/AIDS, who are members of the Dawn of Hope and Mekdim Ethiopia Associations of PLWHA. The purpose was to identify the felt needs and problems of young PLWHA in Addis Ababa in connection with the existing care and support institutions and access to the services they provide.

The major category of need as prioritised by the informants is health care, in the physical, economic and psychological senses.

With regards to health care, the following needs have been identified as requiring close attention:

(i) Access to standard and comprehensive medical services;

(ii) Urgent treatment of opportunistic infections and AIDS-related illness prior to the person becoming susceptible to their weakening effects;

(iii) Regular and continuing medical check-ups by health professionals;

(iv) Cessation of the practice of denying hospital beds to AIDS patients on the grounds that they are terminally ill and there is no cure for the disease. Instead as many hospital beds as are affordable should be reserved for them;

(v) Establishment of a specialised HIV/AIDS hospital where young PLWHA and AIDS patients can easily access the type of medical service they need;

(vi) The provision of home-based nursing and medical treatment to bed-ridden patients with full-blown AIDS;

(vii) Access to anti-retroviral treatment with the administration of the necessary medical procedures.

Physical needs have been prioritised as the second most important. These include nutrition, decent housing, and sufficient clothing. AIDS is known to have debilitating effects on the patient by undermining his or her immune system. Thus, regular and adequate nutritional supplies are a major requirement to enable the patients to withstand opportunistic infections and thereby promote their health. Besides, AIDS patients need a good amount of rest in a home environment free of worry and anxiety to the extent possible. To meet this need, provision of decent housing with modest furnishings is vitally important. As their health deteriorates, patients are confined to the home, in which case they will need adequate and cleaner quantities of bedding. Moreover, sufficient supplies of detergents, cleansers, and insect repellants will be necessary to keep things in a good sanitary condition and prevent further infections.

In the third place, interview and discussion participants have described socio-economic needs of young PLWHA as deserving the maximum possible attention of care and support agencies. Bed-ridden and debilitated patients especially need financial support to deal with day-to-day cares and problems. Others living with the virus but still able to work and fend for themselves also need to be supported financially so that they can be rehabilitated as productive and self-supporting members of the community. Those forced to move to other areas under the pressures of stigma and discrimination by family members, neighbours, and peers seek financial backing to pay house rents among other necessities. They also need support to cover expenses incurred for social activities as well as the payment of school fees, supplies of educational material and uniforms for themselves or their children. Another great social need stated is free and unhindered access to social participation in institutions and events such as burial, women, and youth associations, socio-religious gatherings, wedding and other festivities.

Young PLWHA also have strong psychological needs that they want considered as part of the care and support service. They desire to be shown proper and genuine empathy and affection, which, if they are sure they are given, will strengthen their will to live and their powers to resist the impact of the illness. They feel that they need access to participation in all social activities and events without discrimination. Further, access to regular and continuing counselling services, both home-based and institutional, is very desirable. Finally, there is the need for provision of care and support by family members, neighbours, and home-based care agents in the form of nursing, consistent dietary follow-up, protection against communicable infections, timely delivery to health institution when necessary, supply of adequate information concerning responsible sexual behaviour, and support for regular habits of physical exercise.

Currently Operational Care and Support Programmes

An inventory was drawn up of HIV/AIDS and orphan care and support institutions in Addis Ababa (government, NGOs and CBOs) in order identify the type and coverage of the services provided. Tables 1 and 2 give details the existing care and support institutions for orphans and for PLWHA by type of service provided.

Focus group discussions were conducted on this subject exclusively with young PLWHA who are members of Dawn of Hope and Mekdim Ethiopia associations of people living with HIV/AIDS. Their responses show that currently the bulk of care and support services for PLWHA is being rendered by these two associations, which are so far the only ones of their kind in the country.

HIVAIDS counselling is the single most important service given. The participants in the discussions reported that they have all been receiving regular counselling services on individual and group bases. 'Professional counselling enables us cope successfully with the effects of the virus and the resulting social stigma', they claimed. In fact, a great number attributed their ability to survive longer directly to the counselling that they received. They added, 'counselling imparts the solace and vigour that one truly needs to accept the reality of living

Table 1 : AIDS Orphans Care and Support Institutions

No.	Name of Organisation	Type of Service Provided
1.	Aba Woldethensaye Gizaw Mathers & Children Welfare Association	Medical, Financial and Educational Support.
2.	Abebech Gobena Orphan Project	Medical, Nutritional and Educational Support.
3.	Birhane Hiwot Children's Village & Family Services Organisation	Medical, Financial and Educational Support
4.	CCF-Edget Ber Area Project	Medical, Financial, Material, and Educational Support.
5.	Community Based Integrated Sustainable Development Organisation (CBISDO)	Medical, Nutritional, and Clothing.
6.	Enat HIV orphan project	Medical, Nutritional, Educational, and Housing
7.	Hiwot HIV/AIDS Prevention, Care & Support Organisation.	Financial, Educational, Clothing, and Skill Training.
8.	St. Mary's Orphan Support Program of the Daughters of Charity of the Ethiopian Catholic Church.	Nutritional, Educational, Housing, Clothing, Psychological Sup.
9	Hiwot Ethiopia	Financial, Material, and Legal Support
10.	Yehiwot Tesfa (Counseling and Social Service Centre of the Ethiopian Evangelical Church of Mekane Yesus)	Nutritional, Educational, Housing, Clothing, Psychological Sup.
11.	Hope for Children	Medical, Educational, Clothing, Counselling, Recreational
12.	Mary Joy Aid Through Development	Medical, Financial, Nutritional, Educational, Clothing, Recreational, and Social Support
13.	Medhin Social Centre	Financial, Nutritional, Material, Educational, and Clothing.
14.	Medical Missionaries of Mary-MMM (Counselling and Social Service Centre (CSSC)	Medical, Nutritional, Material, Educational, Clothing, Shelter, and Psycho-Social
15.	Organisation of Social Service for AIDS (OSSA)	Financial, Nutritional, Educational, and Counselling
16.	Pro Pride	Educational, and Counselling
17.	Selame Children's Village	Medical, Nutritional, Educational, Clothing, and Housing
18.	Children AID Ethiopia (SHAD-ET)	Medical, Nutritional, Educational, and Skill Training
19.	Dawn of Hope-Ethiopia	Medical, Material, Educational, Home-Based Care
20.	Mekdim Ethiopia	Medical, Financial, Nutritional, Educational, Clothing, Shelter, and Home-Based Care
21	Woreda HIV/AIDS Council	Financial (School Fee), Nutritional, Educational, Shelter, Clothing, and Home-Based Care
22	Burial Associations (*Iddir*)	Nutritional, Educational, and Clothing.

Table 2: Young PLWHA Care and Support Institutions

Name of Organisation	Type of Service Provided
Medical Missionaries of Mary (MMM)	Nutritional, Financial, Skill Training
Organisation of Social Service for AIDS (OSSA)	Nutritional, Financial, Skill Training
Pro Pride	Nutritional, Financial, Religious, Micro-Credit Facility
Medhin Social Centre	Financial, Nutritional, Material, Educational, and Clothing
Mary Joy Aid Through Development	Medical, Nutritional, and Religious
Hiwot HIV/AIDS Prevention, Care and Support Organisation	Medical, Nutritional, Financial, and Educational
Community Based Integrated Sustainable Development Organisation (CBISDO)	Medical, Nutritional, Shelter, and Educational
Aba Woldethensaye Gizaw Mothers & Children Welfare Association	Medical, Shelter, and Educational
Children AID Ethiopia	Medical, Nutritional, Material, Financial, Shelter, Micro-Credit Facility
Dawn of Hope Ethiopia	Medical, Nutritional, Material, Legal, and Home-Based Care
Mekdim Ethiopia	Medical, Nutritional, Legal, Shelter, and Home-Based
Woreda HIV/AIDS	Financial, Nutritional, Educational, Shelter, Clothing, Home-Based
Burial Associations (Iddir)	Nutritional, Educational, and Clothing

with the virus and facing up to the challenges it involves'. Therefore, they continued, 'we have been able not only to live longer but also feel better and stay healthier'.

Different forms of socio-economic support are another type of service available. Young association members under family care receive Birr 75 per head monthly and those living on their own Birr 150 per head monthly, to help them cover their living expenses. Up to Birr 400 is provided to members undergoing medical treatment to assist them to buy medicine on prescriptions.

Home-based care is a third principal type of care and support service rendered by the associations of PLWHA. It is given to bed-ridden patients and children living with the virus. Trained home care agents, who may themselves be living with the virus provide the service. The involvement of PLWHA in the provision of home-based care has a dual advantage. Besides creating job opportunities, it enables them show in practical terms love and compassion to others under like circumstances. Young PLWHA who served as home-based care agents expressed their thoughts and sentiments as follows:

> Providing home-based care satisfies us the most. Patients feel psychologically restored and empowered when given services accompanied with expressions of commitment, personal interest in them and reassuring words. When they feel healthy and strong enough to do some work, they feel motivated to serve as home-based care agents themselves.

NGOs are the second important institutions implementing care and support programmes in Addis Ababa, next to the associations of PLWHA. Voluntary counselling and testing services (VCT) is a major form of HIV/AIDS care and support provided by NGOs. VCT service enables individuals to obtain personal information they need regarding the modes of HIV/AIDS transmission and the methods of prevention. In the case of infected persons, it provides the necessary psychosocial support to withstand the stress resulting from the knowledge of sero-status. It encourages HIV positive individuals to value life and their relationships with others. Thus, they helped to develop or maintain an optimistic view of life, place things in a realistic perspective and assure themselves that they are still needed regardless of their status. Hence, the VCT service makes up a vital component of HIV/AIDS care and support systems as an effective strategy of control and prevention. The institutions identified by young PLWHA and community members as actively perusing the provision of VCT are Mary Joy Aid through Development, Medical Missionary of Mary Counselling and Social Service Centre (MMM), Hiwot Tesfa, Organisation for Social Service for AIDS (OSSA), and CARE Ethiopia.

In addition to VCT, NGOs are also involved in the distribution of material and nutritional supplies to the PLWHA. These include the donation of grains, cooking oil, clothing, and cash.

A government organisation actively involved in the care and support service is the Woreda HIV/AIDS council, which operates closely with the concerned Woreda administration. With funds from the government and international donors, the council provides beneficiaries with nutrition support, clothing as well as cash for house rent and school fees. It also financially supports bed-ridden AIDS patients. Another major care and support activity the Woreda AIDS council undertakes is home-based care. Through nurses hired at Birr 100 or more, the council sees to it that AIDS patients receive home-based care.

Major grassroots community institutions engaged in HIV/AIDS care and support services are burial association or Iddir. Focus groups of both young PLWHA and community members identified these as key role players in different areas of the campaign. One of these is the care and support service rendered to AIDS patients. In a joint effort with government and NGOs operating in the locality, they distribute food rations and garments to beneficiaries.

The severity of the problem has led to a degree of flexibility and readjustments in community outlook and approach with regard to support for the infected and affected. Pertaining to this, Praag (2000:11) writes: ‘The needs of PLWAs 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 this connection, an increasing number of burial societies are adopting a policy shift in regards to the timing of due cash payments. Traditionally, the policy of most burial societies was such that, upon the death of a member, a fixed sum of money is paid to his or her family to assist them meet necessities for a period. However, considering the needs and sufferings of AIDS patients over prolonged periods of illness, the practice of paying the money to the family after the death of the patient is being reviewed. A chairperson of a funeral association in the focus group discussion observed that members living and suffering with HIVAIDS have actually not benefited from their affiliation with the institution and the financial contributions that they have made for years towards the strengthening of the institution and mutual support of the entire membership. Instead of the AIDS patients who were committed to burial societies until their death, surviving families have been receiving the financial support, which could have been used to take proper care of deceased members while they were still alive.

Reasons for Failing to Access Existing Care and Support Services

This section attempts to investigate the problems that beneficiaries have experienced in the process of accessing care and support services. Factors that preclude potential users benefiting from available provisions are also considered. Singled out as a principal barrier is the practice of withholding services from persons who are known to be receiving support from a certain provider. Beneficiaries realise the rationale behind the reluctance by providers to serve someone who already has some access to a support system. Care and support agencies often argue that they have difficulties getting enough to distribute. They think they get around the problem by reaching only those not served before and thus limiting the number of beneficiaries. Nevertheless, recipients strongly contend such reasoning by pointing out the circumstances of many support-seekers and the lack of coordination among the support systems. Commenting on this, young male and female PLWHA focus group participants sounded single-minded. They remarked that support services rendered by government and non-government agencies are inadequate, minimal and short-lived. The point on their part is that their HIV/AIDS status is forcing them to become heavily dependent on what they can procure from the care and support networks. Currently, the provisions available at a distribution centres are barely enough for the recipients and those under their care.

Not only are supplies inadequate, but they also lack variety, often being one type of item like wheat, teff, barely, cooking oil, etc. Hence, a beneficiary receiving only one of those items from an agency will not obtain other supplies at a different organisation. But one type of foodstuff is hardly nourishing. The need for rations of higher nutrients is much greater in the case of PLWHA. Especially is this true in view of the value nutritional support has in delaying the onset of full-blown AIDS.

Diversity in the services provided fills the needs of the recipients and promotes the cause of the support programmes. In view of this, beneficiaries suggested better donor coordination and follow up as to the continuity, variety and amount of provisions available. They expressed their preference for a diverse support programme that they indicated has a more practical value. They implied that they need lesser quantities of different items rather than too much of one kind. Thus, they proposed support institutions adopt the approach of one of them focussing on beneficiary needs for a particular form of nutritional supply while another deals with their financial requirements.

A young female participant living with the virus said that doing so has a direct bearing on the effort to control the spread of the virus. Elaborating on this point, she told of an encounter she once had. She began by saying:

> One day, I was invited to a wedding party at Crown Hotel. By the time I left the hotel, it was all dark. Luckily, a young man driving a four-wheel vehicle offered me a ride. The driver invited me to sit with him in the front cabin. He greeted me warmly as if we had long known each other. He told me his name and asked if I could tell him mine. Realising his intentions, I introduced myself to him as an active member of Dawn of Hope association of PLWHA. Shocked and stunned, he almost lost control of the car. He remained bereft of speech for some time. When he came back to his senses, he confessed, 'my sister, God bless you! You know I have a wife who is a hostess, and I am a father of four. You spared me great loss and harm'. Dropping me off at my destination, he handed me Birr 50 as an expression of gratitude.

Reports and observations suggest that this experience is not an isolated case. Healthy and attractive looking young PLWHA frequently come into situations where they can lure others or be persuaded to engage in acts of sexual promiscuity. It takes a great deal of social consciousness, humanity and responsible behaviour on their part to resist temptations to engage in sexual practices, especially when the opportunity to make money looks very promising. The young woman quoted earlier suggests that the way to help PLWHA protect themselves and the community in such circumstances is by ensuring that they have access to integrated, consistent, and all-inclusive care and support programmes.

Community representatives who served as key informants for this study observed that NGOs working on HIV/AIDS go about their activities in a less than coordinated fashion. As a result, duplication of programmes exists, a number of agencies concentrating their efforts on certain segments of the population while neglecting others. Strong complaints are voiced in this regard about the coverage given to young people living with the virus in the care and support programmes. According to the key informants, this segment of the community, most affected and threatened as it is by the pandemic, has nevertheless received too little support.

A related problem expressed by these participants is the absence of accurate information about the activities that the various NGOs are undertaking in the fight against the epidemic. The community as well as the beneficiaries are denied the facts concerning service coverage, areas of focus, and type of activities by NGOs involved in the care and support campaign.

Fear of stigma and social isolation is a single major attitudinal factor precluding young PLWHA and AIDS orphans making proper use of existing care and support programmes. In fact, a significant number are inclined or feel freer to access a service when convinced their identity will not be disclosed. For example, most people are encouraged to undergo VCT as an integral part of the general clinical service at health institutions. VCT seekers feel unhindered to visit integrated health centres because onlookers will not directly associate their presence with seeking some type of HIVAIDS oriented assistance. Care and support services are provided largely in the residential areas of the beneficiaries. As a result, many decline to make use of the provisions for fear of being stigmatised by community members as PLWHA.

To qualify for care and support service, PLWHA are required to produce HIV/AIDS certificates and residence identification papers. Failure to meet these requirements has been cited as a chief impediment to accessing existing arrangements. No small number of would-be eligible beneficiaries continues to stay away from support centres as a result. They would rather remain anonymous and miss out on the available services than risk stigmatisation that may accompany processing the required documents.

Trained home-based care agents are greatly involved in the provision of government and non-government sponsored care and support services. These agents are normally fellow community residents of the potential beneficiaries. Rather than risking social discrimination by disclosing their status to the agents and by extension to the community, PLWHA normally prefer to decline to engage with them.

The inadequacy and incompleteness of the provisions have been cited as factors discouraging the young PLWHA from making use of existing arrangements. It was pointed out that the arrangements are not coordinated, one form of care and support excluding other vital components. For example, medical services may not include food provisions without which they mean little, causing beneficiaries not to show interest and motivation in receiving them. Similarly, nutritional support may be provided apart from the payments of house rents, and home-based care without the supply of the necessary furnishings.

Fear of social isolation continues to weigh heavily on the minds of young PLWHA and AIDS patients. Those of them with some possessions or family inheritance strongly favour selling up what they still have and thus survive as long as they can manage, instead of exposing themselves for the sake of receiving care and support.

The inconsistent and sporadic nature of care and support provisions is another reason for the refusal by young PLWHA to join or stay in the programmes. It has been emphasised in the discussions and interviews that especially financial and material forms of support are not provided on a regular basis. They are also hard to predict. Beneficiaries may not be able to anticipate with certainty the next time they are provided. Besides delays, the provisions may be suspended or even terminated without prior notice. Discouraged by the irregularities and uncertainties, beneficiaries may quit, and others who have not yet started will not be motivated.

In too many instances, people become devastated upon realising their status as HIV positive. The state of disappointment and depression causes them to lose purpose and meaning in life for which fundamental reason they generally tend to reject care and support services.

Also obstructing the delivery of HIV/AIDS care and support service are the attitudinal problems reflected by service providers themselves, unwittingly or otherwise. Negative attitudes are reported to prevail at all levels, ranging from the officials and general staff of the concerned government and non-government institutions to professionals specialising in the area. A young male PLWHA reports the following frustrating experience that he had with a Kebele official while applying for cooperation. He said:

> I delivered a supporting letter written on behalf of a fellow PLWHA and myself by Dawn of Hope to the Kebele Administration. The letter requested the administration to consider our circumstance and give us priority so that we could have easy access to a rented home. However, a glance at the subject was enough to irritate him. Looking up, he said to us 'I wish you are not going to ask me for money'. When we told him what we were seeking, he let us move into former latrines now used as dwellings.

Moreover, Kebele administrations are accused of corrupt practices perpetrated against AIDS orphans and vulnerable children. When parents died of HIV/AIDS the orphans have on a number of occasions been made to leave the houses in favour of other occupants. Not only are the orphans denied due support, but what is worse is the abuse committed to promote selfish interests. Members of the administration allegedly negotiate bribes over such houses rather than doing what they can to keep the victims safe and secure.

Many wonder that even places where beneficiaries are supposed to receive the best of care may not after all be the exception to the attitudinal problems reflected by service-providers. The problem manifests itself in different forms. Beneficiaries visiting a health institution for clinical care may be mistreated by whoever is available to provide the service. They could suffer from such things like snubs, scolds or outright insults. Health workers may show themselves fed up of PLWHA, denying them proper care and treatment, as well as demanding more proof for their sero-status than just their official certificates.

Non-governmental organisations engaged in the area of HIV/AIDS may likewise evince wrong attitudes toward the problem as reported by young females living with the virus. They indicated that when they collected monthly allowances at the Organisation for Social Service for AIDS (OSSA), they had to sign with pens apparently meant to be used only by PLWHA. They also alleged that financial support is doled out to them in a manner that betrayed a lack of respect and concern for recipients. Thus, the general mood on the part of the service providers is far from one that makes beneficiaries feel welcome. One of them remarked: 'Their looks seemingly sent the signal that the allowances were handouts after all, and we could take them if we wished, or leave them if we did not'.

Members of all the focus discussion groups have underlined the shortage of medicines as another major problem. They stressed that badly needed medicines are in short supply at government health institutions and available at higher prices at privately owned medical establishments. A great many of them, therefore, fail to obtain medicines that they crucially need due to the shortages at government institutions and their low incomes to buy them elsewhere.

Voluntary Counselling and Testing (VCT) service is another problem area reported. Not all those who may present themselves for the service may necessarily get it. In addition, once they are diagnosed as HIV positive, a counselling service they were promised to encourage them for a test may prove to be not as satisfying as expected. It is not also unusual to be served by VCT councillors whose competence is questioned by beneficiaries. Also mentioned was the quality of facilities at VCT centres. There are allegations that some receive incorrect test results, contributing to fewer people accessing the service.

Restrictions on the category of users are also regarded as a problem in accessing VCT service. In certain neighbourhoods it is said that only commercial sex workers are eligible for VCT. This excludes other community groups in the area from the service. The effort to keep the public informed on the necessity and availability of VCT service has allegedly been insufficient. Despite it being an integral part of the continuum of the HIV/AIDS care and support system, the views and remarks of many suggest that it has nevertheless not been given its due attention. Other problems reported are insufficient number of testing centres at reasonable distances, inadequate public awareness about the necessity and benefit of VCT, limited post-test social and psychological support, shortage of the necessary cash to undergo tests, and irregularities and lack of consistency in the delivery of pre- and post-test counselling services.

Observations are also made of constraints related to the delivery of home-based care. First, home-based agents may not be readily available when needed largely because they are volunteers, doing other jobs to earn a living. Besides the shortage of time and inconvenience as a result, voluntary HBC agents may move to other places for occupational reasons and therefore suspend service provision. Others may interrupt their voluntary work compelled by lack of both consistent training and materials needed for service delivery. Some quit because they are disturbed and discouraged by the deteriorating health condition of patients in their care. Lack of acceptance by beneficiaries has also been cited as a reason why certain home-based agents have discontinued or withdrawn from the service. It is reported that PLWHA tend to reject HBC agents familiar to them or living in the same residential neighbourhoods for fear they will disclose their identity to community members, causing them to become stigmatised and socially isolated.

To sum up, it seems appropriate to quote some comments on the issue by Praag (2000:11):

> Care and empathy for PLWAs are lacking or inaccessible in many parts of the world. Even when health facilities are available, operational and attitudinal problems limit utilization and access to quality care. For example, in East Africa dispensaries and health centres are the first level clinical contact facilities available. These levels are virtually bypassed by people with HIV-related illness for various reasons, including lack of drugs, fear of disclosure of sero-status within the community and poor diagnostic knowledge of HIV-related illness among staff.

Self-Help as a Coping Strategy

PLWHA have developed a number of mechanisms to help them cope with the virus and the stigma associated with it. These mechanisms include tactical or strategic disclosure (disclosing status where care and support may be available and declining to do so where stigma is anticipated) and joining PLWHA networks.

Most PLWHA tend to combine these two strategies to deal with the socioeconomic and psychological consequences of HIV/AIDS. A great number of those involved in the study depended on support provided by relatives, care and support organisations, and associations of PLWHA.

More than half of the PLWHA who participated in the study disclosed their sero-status to someone they trusted, close relatives in great many cases. The outcome has largely been such that they received emotional and practical support after revealing their circumstances. The following statements illustrate that as a direct result of the expressions of sympathy and other kinds of support these PLWHA have succeeded in their efforts to cope with the virus effectively.

> When my husband discovered I was HIV positive, he was far from tolerant. He chased me out of home and I had no one to turn to except my brother. Contrary to my expectations, my brother responded favourably when I shared my secrets with him. The concern and sympathies he showed me helped me greatly to overcome my feelings of loneliness and increased my confidence that I have someone on my side who I can rely on in moments of deep emotional turmoil (A young married female PLWHA).

> It has now been four years since I learned of my status as HIV positive. For the first two years of this period, I kept the secret to myself suffering the consequences alone. After two years though I revealed my status to my mother and sister who, against all anticipations, came to my rescue and took a deep interest in my personal well-being. They responded positively and immediately, extending all emotional and other forms of care and support to the extent they could. This has been the main factor that prolonged my life for the following four years. Without their care and support, I would likely have died much earlier (A young male PLWHA).

Joining care and support organisations and associations of PLWHA as a means of self-help is another of the coping mechanisms used. These networks have proved to be a source of emotional, material and financial support for the PLWHA. They have also been channels of communication whereby information, care and counselling continue to be available to beneficiaries. The practical value particularly of membership in the associations lies in the fact that the PLWHA find a conducive environment that facilitates the sharing of common concerns and sentiments without hindrance. The favourable conditions created by the associations benefit the members by giving them hope for the future and sense of purpose in living that promote an optimistic outlook on life.

An additional practical advantage of membership in the associations of PLWHA and accessing provisions from care and support organisations is that they create forums whereby those living with the virus come together and know each other closely. Prior to joining these bodies, most PLWHA rarely knew another person who lived with the virus. That created the feeling in most of them that they were the only ones who had contracted the virus. The interviews conducted indicate that not knowing another individual sharing the same problem led PLWHA to the mistaken belief that they are a unique people because of the virus and have little hope for success and enjoyment. However, the opportunities that the networks offered them to come together and share experiences helped to correct their wrong views and perceptions of themselves, enabling them to cope with their circumstances in a more realistic and practical fashion.

On this note, responses from focus group discussions and individual interviews overwhelmingly indicate that people whom PLWHA consider especially understanding and sympathetic towards them are fellow HIV positive individuals. The following cases illustrate the valuable role played by networks in the lives of the PLWHA:

> After testing positive for HIV, I could not control my tears and emotions. I was crying loudly, not caring about whoever was there around me. I was more concerned with my children than with myself, believing that there was no one who would support and provide for them. But a young woman who happened to be at the clinic came over and consoled me. She identified herself with me telling me that she too was HIV positive. Assuring me that there were also many other people who live with the virus as I did, she promised to put me in contact with them and facilitate my membership in one of their associations. Her words of consolation helped me pull my thoughts together and stay calm. At the association, I met a number of HIV positive persons with whom I easily mingled and shared personal experiences. I realised that I was not the only one living with the virus. Besides information, the association has enabled me access emotional, medical and other practical support (A young female living with the virus).
>
> I keep talking about the virus with high degree of openness with my friends who are also infected. The more we talk about it, our knowledge about the virus increases and to that extent we learn how to cope with its consequences (A young female PLWHA).
>
> At first, I was reluctant to go to the association of PLWHA, despite the constant advice of my counsellor. I talked to my brother about what I was facing, who then brought me in contact with Mekdim Ethiopia Association of PLWHA. There, I made many friends who also live with the virus as I do myself. Gradually, we became very close to each other, discussing our situation frankly. Especially am I an intimate friend of three members of the association who enjoy an unusual type of company and friendship. We are quick to support each other when one of us is ill or gets into some kind of trouble. Enjoying such special relationships has helped us build cooperative sprit and mutual trust and confidence. It has also shaped our attitudes toward the reality, making it possible for us to accept our circumstance and live with it comfortably rather than trying to dismiss it as if it were not true (A young, divorced woman).

However, even more important than the practical support, as the PLWHA say, is the emotional help that they access through professional counselling, training, as well as the constructive interaction among themselves. A female PLWHA who joined Mekdim Ethiopia after living with the virus in seclusion for five years describes as follows the positive change she has experienced:

> I came to know of my sero-status as far back as 2000. But I could not make up my mind on the question of joining a PLWHA association or applying to care and support institutions. I chose to rely on the practical and emotional help that my family provided. That kept me going safe and sound for as long as three years. During this entire period, I knew no other person who lived with the virus and so I thought of myself as one of the exceptional people who contracted it. Although my relatives were considerate and supportive toward me, we never brought up the issue of my being HIV positive for open and direct discussion. Meanwhile, a turn of events came in my situation in the middle of 2003 when I was suddenly taken ill. My health deteriorated so badly that I thought my final moments of life had at last arrived. The emotional and physical sufferings that resulted from the critical stages of my illness were so excruciating that I nearly decided to commit suicide to avoid further agony. Seeing my condition was terrible and that it needed emotional support besides medical care, a physician advised my relatives to take me to one of the associations of PLWHA. Once I became a member Mekdim Ethiopia, my overall condition improved progressively. For one thing, there I met many people who lived with the virus like myself and shared common interests, experiences and feelings with me (A young girl PLWHA).

PLWHA said that professional counselling was one important aspect of the services provided by the associations and the care and support institutions that brought real benefits in the process of coping with their circumstances. They added that those PLWHA who received intensive counselling and others with adequate training in counselling and home-based care performed a great deal better in coping behaviour than those without this exposure.

Needs and Problems of AIDS Orphans

As stated earlier, children numbering in the tens of thousands have already been orphaned as a result of AIDS in Addis Ababa. It has been forecast that huge numbers will still be orphaned over the coming decade as people continue to die from AIDS-related causes in their child-rearing ages. Thus, orphan-hood being an important facet of the overall national crisis caused by the pandemic, no prevention and control effort is ever complete without duly addressing this growing social menace.

Focus group discussions were conducted in order to identify the problems that AIDS orphans experience under different circumstances. Involved in the discussions were community members as well as AIDS orphans themselves benefiting from some kind of care and support programmes.

The children of people living with HIV/AIDS (PLWHA) and AIDS patients are probably the ones who bear the largest brunt of the HIV/AIDS scourge next to their parents. The impact of the pandemic is known to be multi-faceted, exposing such children to a multiplicity of problems which continue to become more intense and diversified following the loss of either parent or both to the disease. Whether the children are aware of it or not, the prospect of orphan-hood is imminent, especially once the HIV/AIDS positive parents begin to manifest the symptoms of full-blown AIDS. Upon parental loss, the orphans are most likely to be stigmatised in connection with the deaths believed or widely suspected to have resulted from AIDS. It is not uncommon to assume that AIDS orphans themselves carry the virus just because they lost their parents to it. The orphans, therefore, risk becoming the objects of stigma and discrimination by community members, neighbours, peers, and, in no few cases, even close relatives.

Whatever assistance and cooperation the parents used to receive from relatives and associates is very likely to cease after their death, leaving surviving children without care and support. Further compounding the difficulties of the orphans is the failure of the parents to make the necessary arrangements that help the children to cope with the circumstances of orphan-hood. Practice has revealed that parents in a great many cases do not seem to pay much attention to the fate of their children after their death. The problems that AIDS orphans experience in connection with the right to inheritance of family property, land or otherwise, give a clear and strong indication of this fact. Thus, not only do AIDS orphans have difficulties finding relatives coming to their rescue, but to make matters worse, they risk losing part or all of their property rights to those putting forward illegitimate claims.

In desperation, a great number of orphans land up on the streets in an attempt to find food by doing menial jobs or begging. Girls become obliged to sell their labour as domestic servants and exchange sexual favours for cash. While orphaned boys and girls may somehow keep themselves going in this way, street life only increases their vulnerability to a range of further and more complex troubles. The street milieu exposes the orphans to high sexual activity, wilful or forced, with great likelihood of contracting the HIV virus, besides sliding into a number of harmful practices. Children in such situations are hardly able to continue schooling, putting their prospects for a normal life at even higher risk.

While many of the problems cited are common to orphaned boys and girls there are also some that are markedly gender-specific. Upon the death of parents, the responsibilities for the care of the household falls primarily on girls, who thus become burdened with carrying out the bulk of domestic activities. Besides being physically demanding, assuming a leading role in domestic life also takes a heavy toll on the psychology and emotions of the girls in charge. The pressures often become unbearably intense, compelling the girls to seek a way out by practising commercial sex. However, they can feed themselves and their siblings in this way neither adequately nor perpetually. Sex work not only deprives them of their self-respect and sense of decency, but also heightens their exposure to unwanted pregnancies and the chance of infection with STDs including HIV/AIDS. Moreover, acts of sexual violence including rape perpetrated against these girls while still at home or once out in the streets are very likely.

AIDS Orphan Care and Support Services

Currently, a limited number of faith-based and non-government institutions are reported to be active in Addis Ababa in the area of care and support services for AIDS orphans. This study investigated the activities that these institutions and the two associations of PLWHA in the country are carrying out. These are the ‘Counselling and Social Services Centre of the Medical Missionary of Mary (MMM)’, ‘St. Mary’s Orphan Support Programme’ of the Daughters of Charity of the Ethiopian Catholic Church, ‘Yehiwot Tesfa Counselling and Social Services Centre’ of the Ethiopian Evangelical Church of Mekane Yesus, as well as Dawn of Hope and Mekdim Ethiopia associations of PLWHA.

Information was gathered on the types of services provided through interviews with the staff of the institutions and focus group discussions with beneficiary orphans. This component of the research revealed that the existing care and support services targeting AIDS orphans basically include food, shelter, and clothing provisions, health care, psychological support and supplies of educational and related material. The institutions provide food rations to the orphans whose living circumstances vary according to their particular experiences. There are those who remain in an extended family setting despite the loss of one parent or both to HIV/AIDS. Others find themselves in child-headed households, in which case the eldest of the surviving children usually takes over responsibilities following the death of the parents. The institutions also make arrangements for orphaned children to share group homes in situations where there are no close relatives to take them into their homes, or the orphans have for different reasons lost shelter as well. The food rations include wheat, famiex, and cooking oil. It is reported that the food rations given to the beneficiaries in extended family structure do not get them through to the next round of monthly rationing. The insufficiency is attributed to the limited amounts of food aid made available to the institutions by donor agencies. However, the centres report that they make every possible effort to see to it that orphans in group homes obtain regular and sufficient food provisions at reasonable time intervals. The Yehiwot Tesfa, one of such institutions, provides cash rather than food items with which the beneficiaries or their guardians themselves buy food supplies.

Clothing and school uniforms are provided to the orphans once a year. They are also given money to pay house rent, and in the case of those in group homes, the institutions settle the house rents.

The orphans are also provided with basic health services mostly at clinics operated by the care and support institutions. The poor living conditions of the children generally make them vulnerable to different parasitic and infectious diseases such as typhoid and diarrhoea. The nurses at the clinics treat the children for these and other illnesses, referring major cases to higher health institution for further medication. The centres cover the medical costs of the referral cases.

Psychological support makes up a significant component in the care and support programmes that the institutions are implementing. This type of service is vitally important to children who have experienced the loss of parents in their tender years. The grief and distress associated with the bereavement results in emotional disturbance and stress that the surviving children find beyond their means to cope with. Their depression is further aggravated by the difficulties they continue to experience in their efforts to get on with life and adjust to their losses. A single dominant expression of their psychological state is the behavioural problems that they tend to exhibit around the home and beyond. The institutions identify orphans with special care and support needs in this area by way of information gathered from family members and close neighbours. Once identified, they are given counselling services through regular home visits or by appointments at the counselling centres.

As well as the aforementioned services, orphans in these programmes also receive educational support to ensure that they continue schooling despite their circumstances. The educational support involves supplies of school materials and uniforms and the payment of school fees. Yehiwot Tesfa provides the cash to enable beneficiaries get the needed supplies, handing out Birr 50 monthly per child for educational materials, and Birr 200 annually for school uniforms and shoes. A school fee of another Birr 120 is also allocated for each beneficiary.

Through negotiations with the concerned school administrations, arrangements are made by the institutions so that school fees are waived for orphan children. For motivational purposes, students with the best performances are awarded prizes in the form of cash or educational materials.

In addition, the institutions support the orphans in connection with their rights to property inheritance. This is reported to be one of the major problems that AIDS orphans encounter and need external assistance to properly handle. Therefore, the organisations discussed in this study incorporate into their programmes some support for beneficiaries with regard to property rights. First, they approach responsible members of the extended family to address smoothly the dispute. If that fails, an effort is made to peacefully resolve it by involving in the matter a committee of elders close or acceptable to the family. In extreme cases, the institutions take the case to organisations who can lend legal support so that the property rights of the orphans are respected in courts of law.

The majority of the orphans receiving care and support services in these institutions are known to live with members of the extended families. This is in line with the policies of the government and organisations catering to the needs of AIDS orphans. These bodies encourage community-based care and support rather than institutionalised support systems such as orphanages, which should only be a last resort.

Thus, the centres take the necessary measures to contact the closest relatives of their clients who have died of HIV/AIDS and leaving children behind. The purpose is to persuade the relatives to take over the responsibility for the care of the orphans. There are times when family members of the deceased may of their own initiative approach the institutions in the hope that the support will continue after the death of the client and that they can now access it by fostering the surviving child. In other circumstances, the children of the deceased clients themselves may connect family members with the care and support institutions.

However, whatever the means of contact, family members respond differently with regard to care of the orphans. Some have gone as far as offering to take the child away into rural villages where they themselves reside. Moving to live and grow up in a strange environment can, however, have undesirable effects on the child, as experience has shown. The maladjustment, coupled with the psychological stress resulting from the parental loss, could make things extremely difficult, seriously affecting the future prospects of the orphan in care. Nevertheless, a most widely observed response by family members is unwillingness to commit themselves to the care of the orphans and accept them as part of their family. In fact, there are some who deny any blood relationships or simply disappear after realising the cause of the death and the intentions of the institution.

When no family member is thus committed, the centres make alternative arrangements to ensure the orphans get the necessary care and support. They arrange for the orphans to live in groups in rented houses where a foster mother is employed for them to take care of their day-to-day needs. Group homes enable orphans to learn to manage their lives independently, gain experience through social interaction, and grow up in the community where they were born, without socially dislocated and therefore needing assistance with the process of readjustment.

Other than group homes, arrangements are made for adoption to take care of orphans who are not in a position to live with their extended families. Accordingly, the institutions receive and process requests from interested adopters or themselves initiate contacts in a bid to find potential adoptive families. They make adoption arrangements for the children both with families within the country or abroad. Before an adoption takes place, however, certain issues need to be addressed. First, the personal choice of the potential adopters in regards to the age and sex of the adoptees has to be considered as a matter of priority. The government is also involved in the process through the Child and Youth Affairs Department of the Ministry of Labour and Social Affairs and the grassroots unit of city government, the Kebele Administration. The former issues approval for the adoption to take place after considering the case from the legal and administrative points of view. Based on the information from witnesses, the Kebele Administration must confirm in a supporting letter that a child is genuinely an AIDS orphan for the process of adoption to commence. It is the role of the care and support centres to follow up on the progress by maintaining regular contacts with potential adopters, foreign or domestic, via correspondence and other means.

As already suggested, institutional care for orphans should only be arranged as a final option, having exhausted all possibilities to arrange for them to live with extended or adoptive families. However, institutional care becomes a necessity in situations where none of the aforementioned arrangements proves to be practical. Thus, a resort to orphanage becomes inevitable in the absence of extended family members showing an interest in taking care of the orphans, or when there are disparities between potential adoptive parents and children needing care, or with the physical and emotional inability of the orphans to stay in a group home setting. Compelled by these circumstances, the Counselling Centre of the Medical Missionary of Mary (MMM) alone reports having placed up to thirty children in an orphanage.

Orphan care and support furnishes an important form of service rendered by the associations of PLWHA, Dawn of Hope and Mekdim Ethiopia. To provide a service, the associations first investigate whether an orphan lost one parent or both due to AIDS. Once they establish AIDS as a cause of orphan-hood, they enrol the victims as association members. Following this, an assessment will be carried out about felt needs of the orphans through group counselling and discussion. Accordingly, the following services will be available to eligible orphan beneficiaries:

(i) For orphans living with the virus there is nutritional support and provision of house rent and medical care.

(ii) For orphans needing in-house care, nurses are hired to cook their food and do their cleaning. Dawn of Hope is at the moment caring for twenty AIDS orphans through hired nurses and guardians at a group home organised for this purpose.

(iii) For school age orphans a supply of educational materials and school uniforms are provided twice a year.

(iv) For orphans tested HIV negative, arrangements for adoption with interested volunteers, local or foreign, may be made. In this effort, Dawn of Hope has made adoption arrangements for a number of such orphans in the United States.

(v) On public holidays arrangements are made marking major holidays such as Christmas, Eastern, New Year's Day, Id Al Fater (Ramadan) so that orphans may celebrate them as the rest of the community do. With funds raised from different sources, special foods are served besides some cash provision to assist the beneficiaries.

Summary and Recommendations

Summary

On the basis of the information obtained from young people living with HIV/AIDS and AIDS orphans, their most important needs can be stated to be health care — physical, socioeconomic, and psychological. Thus, they singled out as the first high priority need for the provision of affordable, comprehensive and specialised medical service. The study population emphasised the importance of tailoring the proposed health services to the needs and conditions of the targeted beneficiaries. This suggests that the packages be inclusive of the treatment of opportunistic infections, counselling and psychological support, and home-based care and nursing.

The study participants prioritised physical and socio-economic needs as the second most important. Low standards of living, poverty, and the weakening of the body's immune system are reported to aggravate these needs. Provisions of a physical and socioeconomic nature basically encompass nutritional support, and supplies of shelter and clothing. The nutritional aspect of such support stands out as the most prominent since it plays an important role in strengthening the body's resistance to infection and improving the health condition of the infected. The need for decent housing has been described as the next biggest. Evictions from rented houses and hardship in maintaining or securing a new one are among common stories forming the pattern of mistreatment that young PLWHA often experience at the hands of house owners and neighbours. Particularly is this the case with AIDS orphans. Quite often, they are left homeless upon the death of their parents. Reportedly, those who rent out houses — public and private alike — resort to forcing helpless orphan children out of their shelters once their parents have passed away. To make matters worse, their plight may not end there. Dislocated from their once secure abode, the victims often find themselves vulnerable to various forms of abuse, including sexual assaults in the case of orphan girls. Homelessness also generally causes these orphans to go out to the streets, where they are exposed to a number of risks, contracting HIV/AIDS being a most likely one.

Emotional and psychological needs come fourth in order of priorities that young PLWHA and AIDS orphans underscored in the course of the study. It was not difficult to gauge from a reading of their responses the extent of their hunger for social acceptance and expressions of empathy. They expressed a general feeling that the rehabilitation component of the national HIV/AIDS policy has not gone far enough in addressing such critical needs. This is shown by the fact that the available care and support services dealing with this aspect of the problem prove to be inadequate compared with the size of the existing demand.

The other point of focus in this study has to do with the existing care and support services for young PLWHA and AIDS orphans in Addis Ababa. Thus, a survey was made of such institutions operational at the time of the study. According to the information provided by the beneficiaries, the associations of PLWHA, Dawn of Hope and Mekdim Ethiopia carry out the largest percentage of care and support activities in the metropolis. The major aspect of the service rendered is constituted by professional HIV/AIDS counselling and psychological support. Other types of services the associations provide include material support, orphan care, legal support, home-based care, and financial assistance to cover medical costs. Home-based care (HBC) in particular continues to be one of the chief areas of focus to which these associations are attaching ever-greater importance. Both the caregivers and recipients stand to benefit from the great emphasis laid on HBC, as they themselves acknowledged. The job opportunities created as a result of this type of service enable members of the associations to gain access to gainful employment. Moreover, the caregivers, who are themselves HIV-positive, will be in a position to serve others under like circumstances with such empathy and commitment that the nature of the job demands.

Community members who participated in this study identified government and non-government agencies, Community-Based Organisations (CBOs), youth associations and anti-AIDS clubs as the other bodies that play an important role in the provision of care and support services to PLWHA and AIDS orphans.

Voluntary Counselling and Testing (VCT) is reported to constitute an important part of the continuum of care and support services provided by indigenous and international NGOs. Key informants and focus group discussion participants singled out the NGOs that are actively involved in this type of service. These are Mary Joy through Development, Medical Missionary of Mary Counselling and Social Service Centre (MMM), Hiwot Tesfa, Organisation for Social Service for AIDS (OSSA), and CARE Ethiopia. The information obtained shows that VCT services are available to AIDS orphans and vulnerable children for free, and only at token payments to other clients.

The city government is also involved in the provision of care and support services to young PLWHA and AIDS orphans. The HIV/AIDS Council, which body is structured at sub-city level, utilises resources made available by the government and donor agencies to meet the needs especially of those with full-blown AIDS. Besides nutritional support, the council makes cash provision to cover housing, clothing and medical expenses. It also ensures the deployment of nurses to carry out HBC activities. In addition, the AIDS Council operates, in collaboration with the Kebele administration, Iddir societies and youth associations, to conduct Information, Education, and Communication (IEC) programmes.

Grass-root organisations, Iddir (burial societies) in particular, are gaining increased prominence in relation to their involvement in HIV/AIDS-based care and support programmes. As well as playing an active role in community sensitisation and educational campaigns against the pandemic, burial societies contribute a good measure of socioeconomic and material support to the infected and orphaned. Burial societies have also become an important force in another way in the effort to halt the spread of HIV infection. Agencies involved in the delivery of care and support services use the leverage that these grassroots institutions command over community members to promote their programmes.

This study has also dealt with problems that PLWHA and AIDS orphans encounter as they try to access existing care and support services. Clients observed that inadequacy and duplication of services and lack of coordination among providers are some of the constraints they experience. The shortage of clear information and non-transparency concerning which agency is providing what type of service is another problem cited. Failure to access such information is said to have hindered effective utilisation of the existing continuum of care and support services. Moreover, beneficiaries brought up the point that their actual felt needs are not usually taken into consideration in the designing and implementation of programmes meant to address their problems.

The study population expressed in strong terms their dissatisfaction regarding the scarcity of drugs for the treatment of opportunistic infections. Even when available, anti-retrovirals continue to be unaffordable for most of those in need of them. They also stressed as a major shortcoming the state of low public awareness about the need for voluntary counselling and testing, and the continuing general reluctance to access the existing VCT service.

Recommendations

Young PLWHA, AIDS orphans and community members who participated in this study have made the following recommendations regarding the necessary remedial measures to adopt in order to improve the quality and size of the current care and support programmes.

(i) Facilitating the necessary conditions for the provision of comprehensive medical care to young PLWHA, AIDS orphans and affected families. Supply of antiretrovirals at subsidised prices.

(ii) Making available sufficient nutritional support.

(iii) Ensuring that they find decent homes or supporting them financially to pay house rents.

(iv) Making provision of materials, clothing, and home furnishings as the need may be.

(v) Training family members in the delivery of care and support.

(vi) Making the necessary arrangements for the provision of regular and consistent counselling services. Offering counselling service at individual home level. Establishing social committees to deal with the psychological problems of young PLWHA and AIDS orphans.

(vii) Enabling PLWHA take care of themselves through the provision of skill training to those capable of active engagements and their family members.

(viii) Encouraging community participation at all levels in this endeavour from planning to evaluation.

(ix) Ensuring that the effort is coordinated in collaboration with government and NGOs and CBOs in the area.

(x) Strengthening the home-based care service by way of sufficient training and material incentive to the agents. Building their capacities through refresher courses and updates on current information about HIV/AIDS.

(xi) Support to orphans and vulnerable children so that they will not quit or drop out of school. Skill training to those old enough to take up a job. Additional educational support outside school.

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