

Full Length Research Paper

Community home based care for people living with HIV: an overview of client needs, actors and services provided in Ethiopia

Mirkuzie Woldie^{1*}, Morankar Sudhakar² and Garumma Tolu Feyissa²

¹Department of Health Policy and Management, Jimma University, Jimma, Ethiopia.

²Department of Health Education and Behavioural Sciences, Jimma University, Jimma, Ethiopia.

Received 28 April, 2015; Accepted 25 June, 2015

In Ethiopia, it was shown that funding levels are far from compatible to the needs for care and support services for people living with human immuno-deficiency virus (PLHIV) and orphaned and vulnerable children (OVC). The aim in this study is to map the relationship between client needs, actors, care and support services provided for PLHIV and OVC in Ethiopia. A case study of the Ethiopian community care program was carried out using multiple methods of data collection as part of a multi-country research of four countries. Three program cases providing care and support services throughout the country were studied. A total of 35 in-depth interviews, 9 focus group discussions, 60 guided interviews, and 3 community mapping exercises were carried out. Analysis was conducted using the thematic framework approach with coding and mapping of the transcripts in the ATLAS.ti version 5.0. The expansion of antiretroviral therapy (ART) has reduced the number of bed-ridden PLHIV in need of home based nursing care. Currently, inadequate access to food and lack of income to cover health care and other expenses are the major concerns of PLHIV in Ethiopia. Community Home Based Care (CHBC) in Ethiopia can be categorised into two types; clinical and non-clinical. Non-clinical care (psychosocial, economic, home nursing care, material, food, and other social supports) is mainly provided by non-governmental care-giving organizations. Clinical care was provided mainly by government health facilities which comprised services such as early detection and treatment for opportunistic infections (OIs), ART services and PMTCT. A clear shift of the need of PLHIV from basic nursing care at home to social and material support needs was observed. A coordinated effort from the key players including governmental entities, non-governmental organizations (NGOs) and faith-based organizations (FBOs), the community, associations of PLHIV and volunteers is required to meet the current needs of PLHIV and OVC in the country.

Key words: Caregiver, community home based care, patient needs, service provision, care and support, people living with human immuno-deficiency virus (PLHIV), Ethiopia, qualitative methods, mapping.

INTRODUCTION

Before the introduction of Antiretroviral Therapy (ART) in sub-saharan Africa, Community Home-Based Care

*Corresponding author. E-mail: mirkuzie@yahoo.com

Author(s) agree that this article remain permanently open access under the terms of the [Creative Commons Attribution License 4.0 International License](https://creativecommons.org/licenses/by/4.0/)

(CHBC) programs were developed as an unsystematic and need-based effort to meet the demand for palliative care in absence of (or limited options for) medical care at health facility level (Ncama, 2005). These later developed into organized services as part of the HIV prevention and control response by governmental and non-governmental organizations.

A sub-Saharan multi-country study showed that CHBC is effective and affordable for people living with HIV (PLHIV) and has a positive impact on the health and social status of patients, families and the community at large (Mohammad and Gikonyo, 2005). Though the contributions of CHBC have been significantly popular before the introduction of ART, they still prove to be important in taking care of the needs of PLHIV even after enrolment into ART services. A study in sub-Saharan Africa indicated that patients exposed to community-based supportive services experienced a more rapid and greater overall increase in CD4 cell count than unexposed patients. In the study, the patients also had higher levels of adherence, attributed primarily to exposure to Home-Based Care (HBC) services (Kabore et al., 2010).

In addition, an article concluded that HBC potentially reduces stigma, thus improving uptake of HIV testing, and access to care and support (Alison et al., 2010). Reported community care programs are confronted with many unmet needs of clients. A Nigerian study reported that nearly 80% of the subjects reported unmet health needs out of which medication needs were most often unmet (48.3%), followed by HBC. It was noted that HBC was lacking and more PLHIV were forced to find treatment in hospitals (Adedigba et al., 2008). This is contrary to the fact that HBC services emerged because patients could not easily access services at the health facilities for several reasons. In Guyana, it was reported that not all clients had access to safe drinking water and some experienced difficulties in tasks, such as sitting, standing, lifting, carrying, pushing or pulling. There were also worries about the quality of care and some volunteers did not meet the needs of the respondents. Another unmet need was the desire to receive job and skill training. Mainly, the respondents reported unmet needs in the areas of economic opportunities, food and children support (Boryc et al., 2010). Before the introduction of ART, PLHIV in Ethiopia fully depended on the goodwill of the community and NGOs to support them during their illnesses and in dying with dignity (Aantjes and Jerene, 2010).

On the basis of information obtained from PLHIV and community representatives, the most important needs of PLHIV at that time were emotional and psychological, physical and socio-economic, clinical and health care, legal and human rights (Hailu and Stuer, 2002). Stigma surrounded PLHIV even in the health facility (Feyissa et al., 2012) where their health care needs were only marginally addressed. However, as of 2005, PLHIV are increasingly accessing free ART and the majority of their

medical care needs are now being addressed by public health facilities. As a consequence, the emphasis in their demands has shifted from basic nursing care in the home to nutritional and material support and means of income generation in the long run (Aantjes and Jerene, 2010). Cognizant of the contribution of community care programs implied by reports from different countries is a multi-country study on the historic development of care-giving, its evolution, extent of integration into existing health system(s) and potential role in expanded HIV and PHC programs was initiated by the Care-givers Action Network (CAN), Cordaid and United Nation's Joint program on HIV/AIDS (UNAIDS).

In this article, we are reporting findings on client needs, actors involved and service provision in the Ethiopian context. Focus on the relationship between client needs, actors, care and support services provided is timely, given the fact that there are needs of PLHIV which are not met by the formal health system of the country (Aantjes and Jerene, 2010). Hence, the questions we intend to answer in this article are: What are the felt needs of PLHIV? What is the role of community home based care activities in meeting these needs? Who are the key actors and what specific roles do they play in the provision of care and support services to PLHIV in Ethiopia?

MATERIALS AND METHODS

Study design and participants

Ethiopia was part of a multi-country study conducted in 2011. Other African countries in this study included Malawi, South Africa and Zambia. In each country, in-depth case studies were conducted among three large care-giving organizations following a phased research approach. The cases were selected on the basis of the following criteria: care-giving organizations running their activities in most or all parts of the country and those older than 10 years. This was supplemented by the recommendation of the Advisory board of the research project. Accordingly, two of the three cases (OSSA-Jimma and Medan ACTS-Hawassa) were taken from the two largest regional states in the country while the third one (Mekdim Ethiopia-Asossa) was taken from an emerging regional state. Three big care-giving organizations namely; Mekdim Ethiopia National Association of PLHIV and AIDS Orphans in Asossa, OSSA in Jimma and Medan ACTS in Hawassa were taken as model care and support organizations and included in the study. The major actors for national level interviews and the three large care-giving organizations were selected by the Advisory Board (composed of key governmental and non-governmental organizations and community volunteers) and were considered to be representatives (models) of care and support activities in Ethiopia. The study's participants included a group of senior managers who represent major national stakeholders of care and support for PLHIV situated in the capital city of Ethiopia, Addis Ababa. For each of the three cases, managers, program officers, community representatives, clients, primary caregivers and community volunteers (secondary caregivers) were included in the study.

Data collection procedures

A common research protocol guided the research process in all of

the four countries. All of the tools used in the study were developed by the coordination team of the multi-country research and further contextualised by the country research team with the help of the Advisory Board. There were different phases in the conduct of the study. During phase 1, we conducted 10 in-depth interviews with national representatives of major players of care and support activities in Ethiopia. In the second phase, data were collected from the managers, program officers, community representative, clients and community volunteers relating to the three cases. A total of 25 in-depth interviews and 9 FGDs were carried out with managers (of public health system and care-giving organizations), program staff of NGOs¹ community representatives and volunteers. Guided interviews were conducted with 30 clients and 30 primary caregivers (10 for each case in both categories). Community mapping of key actors of care and support activities relating to each of the three cases was performed by participants of the FGDs with volunteers with verification by community representatives. Interviews were conducted by the principal and co-principal investigators of the country research team with the assistance of four researchers who had ample experience in qualitative data collection. All of the interviews were recorded with a digital voice recorder and notes were taken to assist the transcription of the interviews. All the interviews were conducted in Amharic.

Data analysis

After completing the data collection, verbatim translation and transcription of the recorded interviews was done by the research assistants involved in the interviews. Then coding of the transcripts using ATLAS-ti 5.0 software was performed based on the common codes created for the multi-country research as a whole. Query reports generated by ATLAS-ti were used to analyse and narrate the research findings. Based on the reports from the first two phases, a concluding validation phase with additional data collection was carried out. In this phase (phase 3), telephone interviews with four national level key informants were carried out to validate the main findings of the countrywide study. Validation of research findings among medium to large care and support organisations in Ethiopia was also conducted through a questionnaire to which 10 of the 13 care-giving organizations contacted responded.

Ethical considerations

The protocol for the conduct of this study, contextualized from the multi-country protocol, was ethically cleared by the Ethical Review Board of Jimma University and the VU University of Amsterdam. Written and signed consent was obtained from each of the study participants before their involvement in the study. In case of minors who were included in the primary caregivers' interview, assent of the respondents and consent of their parents were obtained. All of the data obtained from the participants were not linked to any personal identifiers and were accessed by the research team only. All digital records of interviews and discussions for the research were destroyed after transcription was finalised.

¹ The rationale behind selecting older programmes is that there is a wealth of information and experience within these programmes. Such programmes would have been able to (firmly) establish themselves, adapt to contextual changes and achieve a level of embedding within the community and linkages with other actors in community care. Importantly, they would have provided services to people living with HIV both when ART was and was not available, offering an important perspective regarding the changes seen over time. It is this type of evolution that we would like to bring to the fore in the country case study.

Operational definitions

Primary care-givers are family members and friends who provide immediate care to family members and/or loved ones. Secondary care-givers are care-givers who work on an individual basis or as staff on a paid, unpaid or voluntary basis at clinics, for non-governmental organizations (NGOs) or for the government. As such, the term secondary care-givers refers to both employees of health ministries and of NGOs, including faith-based organizations (FBOs), while community care-givers refers to both primary and secondary care-givers.

RESULTS AND DISCUSSION

Description of the study participants

As it was already implied in the methods section, senior managers representing major players of care and support for PLHIV and three model care-giving organizations were included in this study. There were 10 key informants involved in the national level in-depth interviews. A total of 25 managers (of public health system and care-giving organizations) were interviewed as key informants. Each of the 9 FGDs had 6 to 10 participants from community representatives, program staff of NGOs and community volunteers. Three FGDs were conducted, one for each of these groups, for every care-giving organization. In the guided interview with clients (beneficiaries) and primary care-givers, 10 participants were interviewed from each category for each of the three cases (n = 60). Twenty four (80.0%) of the 30 beneficiaries interviewed were females while 15 (50.0%) of the 30 primary care-givers interviewed were females. The age of the primary care-givers ranged from 11 to 50 years of age and 8 (26.7%) of these were younger than 20 years. Majority (70.0%) of the beneficiaries had age of 30 years or older with only one client younger than the age of 20 years.

Patient needs

In the 1990s, care and support of PLHIV was started in Ethiopia by some NGOs like Mekdim Ethiopia and NEP+ because of the following reasons; first, there was no sort of treatment for PLHIV. The only treatment available during that time was psychosocial support and basic nursing care in the form of symptom relief. Secondly, there were large numbers of bedridden PLHIV who were in need of care and support. Thirdly, stigma and discrimination against PLHIV was very high.

Finally, during those days, the hospitals were busy with AIDS patients. As a key informant from Addis Ababa HAPCO described, out of the total hospital beds in Addis Ababa, 60% were occupied by AIDS patients. It then became challenging to give treatment at health facilities. As a result, there was a need to engage communities in care and support services so that HIV/AIDS patients would get the necessary support at home resulting in task shifting to primary and secondary care-givers. There is a

common understanding among almost all key informants that in the early 1990s, many of the PLHIVs were bedridden and they needed more intensive home based care. During that time, volunteers (who were very few in number) were overloaded in the provision of HBC. By then, home based care was thought to be providing physical care alone, such as hygiene, treatment of opportunistic infections (OIs) and facilitating ART enrolment when it became available (2004/2005) at the health facilities.

Later on, psychosocial aspects of care, such as nutrition, psychological support, social support and economic support, were included in the home based care package. Attention was also given to the prevention of exposure to the virus by the volunteers. During the last decade, changes have been observed with regard to the needs of people living with HIV in Ethiopia. The increased access to ART has resulted in a clear shift in their needs from basic nursing care in the home to livelihood support, including food security, other material support, and means of income generation.

The successful scale up of ART and its implication in the country has been reported earlier (Assefa et al., 2009). Moreover, similar pattern in the shift of needs following ART use among PLHIV has been documented in Malawi, South Africa and Zambia (CAN, 2013). Clients and other respondents interviewed in the study indicated that the main problem of PLHIV currently is a shortage of food and lack of livelihood to cover other expenses. This was mainly related to the loss of jobs following a positive HIV status. Moreover, participants commented that most people affected by the HIV have financial problems. Only few of them are government employees with the majority having unreliable means of income.

Food by prescription (FBP) at government health facilities providing ART has been initiated using the BMI of the client as a criterion. However, clients with a normal BMI may as well not have anything to eat. whereas, clients previously had access to food support from the care-giving organizations. The study observed that this is no longer the case following the reduction of funds available to the care-giving organizations. During the validation interviews, all of the informants reported that their organizations perceived nutrition to be a growing and particular need of patient on ART.

However, it was also indicated by some that the nutritional need for patients on ART should not be over emphasized. While admitting the importance of this need, one key informant noted, "... there is an exaggeration of this need by the people (staff of the NGOs and FBOs, clients and volunteers) since they assume that PLHIV need special diet while on ART.' He recommended that 'if the patients take whatever is available as usual' this problem may not be as significant as it appears. Another informant added that 'patients have the misconceptions of the need for special food while taking ART medications'. This finding illustrates the different opinions

that exist on patient needs in Ethiopia. While patients depend on the support services received from various institutions in the country, they also indicated that this is not sufficient. Primary care-givers and clients implied that majority of the PLHIV want to get involved in income generating activities (IGAs) following the health improvements they get after ART. For that purpose, they need initial capital or seed money and skill training. However, some PLHIV are not skillful enough to save money and therefore they need lifelong support. Moreover, there are PLHIV who do not have relatives or care-givers at their home requiring home based nursing care by a secondary caregiver. Key informants mentioned that nowadays, the need for economic support among PLHIV is extremely high. Particularly, widows and orphans are in serious conditions and they need psychosocial and economical support.

Moreover, the living cost is becoming increasingly expensive, thereby aggravating the troubles faced by the PLHIV. There are also many clients in need of shelter. Moreover, many PLHIV do not have job security, when they remain in bed everything will stop, they also exhaustively use their resources, they do not have capacity to be productive and they are psychologically affected. Moreover, there are PLHIV who do not have a relative or care-giver at their home and there are so many OVCs in the towns. The number of AIDS orphans in Ethiopia was estimated to be 800,000 to 1.2 million (UNAIDS, 2000; AHOPE, 2005). These children need to be supported in order for them to continue their education, eat adequate food, pay schooling expenses and have shelter.

The conclusion that 'PLHIV today in Ethiopia predominantly have support needs as opposed to basic nursing care at home' (Aantjes and Jerene, 2010) was confirmed to be correct by the key informants during the validation interviews. While the informant from the Federal Ministry of Health (MOH) estimated that the proportion of PLHIV who still need basic nursing care is 25% throughout the country. The respondent from the Addis Ababa HAPCO claimed that this proportion has now come to close to zero percent in Addis Ababa. This relates to the fact that ART coverage for eligible patients is much higher in the capital because of the better access to health facilities providing the services. The WHO estimated that the ART coverage of Ethiopia in 2012 was 61%, most part of which is contributed by big cities including Addis Ababa (WHO, 2013).

This resulted to care-givers being limited to mainly provision of support services including food, shelter, and economic support particularly in urban centers. The table below provides the list of unmet needs as identified by the clients of the care-giving organizations (Table 1). The major achievements of care and support organizations, since their appearance 8 to 11 years ago, as listed by participants include:

(1). Improvement in the economic status of clients.

Table 1. Services missing in the study areas as commented by clients of the care-giving organizations.

Type of service	Service availability	Implications
Health services	It was free in the past and NGOs covered costs of all services. Now, clients have to buy drugs except for ART and laboratory tests. In Kebele, there is no more support letter for free drugs. While in Idirs, they do not allow purchasing drugs from private pharmacies and drugs are mostly not available at the government health facilities.	Weight loss, problem in ART adherence, coming back without purchasing drugs and some may be obliged to visit traditional practitioners
Food support	In the past it was available for free. Now NGOs are no more able to provide due to lack of funds.	Weight loss, immunity worsening and health professionals complain about ART adherence
Shelter	Before, house rent was paid by NGOs. Currently there are no such supports leaving the clients without a shelter.	Owners ask for house evacuation when client is unable to pay who is always worried about this. May forget to take ART and other medicines as scheduled due to the stress
Hygiene facilities	No latrine No drainage system No safe water to drink Use of spring water, and is usually not well protected	Poor environmental hygiene. Frequent gastro-intestinal up set. Frequent malarial attacks
Basic nursing care	Earlier provided by volunteers supported by the NGOs. Now discontinued due to lack of funds	Missing those days of care and affection. No chance of getting reminders for ART adherence and other health information. Some do not have anybody to care for them

*Kebele is the lowest administrative unit in the country; ** Idir is an association established among neighbours to raise funds that will be used during emergencies, such as death within these groups and their families.

- (2). Improvement in the nutritional status of clients.
- (3). Improvements in ART enrolment and adherence.
- (4). Reduction of death from AIDS.
- (5). Reduction of stigma and discrimination against PLHIV.
- (6). Provision of shelter and clothing to PLHIV.
- (7). Support of OVC to complete their school (some have joined university).
- (8). Increased uptake of VCT and PMTCT.
- (9). Empowering Idirs to take up the role of care-giving.
- (10). Establishment of self-support/help groups.
- (11). Urban gardening programs (in school OVC).

Actors and services provided to PLHIV

In the Ethiopian context, HBC consists of two components: clinical and non-clinical services. Non-clinical care consists of services such as psychosocial support, economic support, materials support, food, and other social supports. Clinical care provided by the MOH facilities include provision of services such as

early detection and treatment for opportunistic infections (OIs), ART services, and PMTCT. Non-clinical services are provided by different organizations, ranging from individuals to both local and national governmental and non-governmental organizations.

Although the government sector coordinates these activities, in Ethiopia HBC is mainly supported and delivered by NGOs and their volunteers. Caregiver organizations, local self-support groups and different government organizations provide and facilitate the care and support services, whereas, volunteers, mother support groups and primary care givers are involved in providing physical and psychological support at home. On top of their leading role of directly providing care and support, NGOs are directly involved in the mobilization of resources and the community.

For example, OSSA is involved in organizing income generating activities for PLHIV, community dialogue, discussions, information dissemination through various mechanisms, condom distribution, and VCT services, establishing anti-AIDS clubs in schools and out of schools. The key informants from OSSA mentioned have

established more than five hundred clubs throughout the country. Moreover, OSSA has different VCT service modalities which include mobile, standing, home based and outreach VCT. The Network of HIV Positives (NEP+), an umbrella organization for associations of PLHIV, works on developing the capacity of associations of PLHIV through trainings, advocacy, resource mobilizations and greater involvement of PLHIV in response to the epidemic. Once PLHIV recover from their acute conditions, these associations provide economic support through involvement in IGAs. NEP+ is also involved in the capacity building of faith based organizations working on HIV/AIDS related activities. As a part of the capacity building, they undertake different activities such as resource mobilizations, capacity building activities in terms of finance, materials, technical and institutional capacity building.

They also have other social accountability programs such as environmental protection, natural resource management, food security, and gender and development issues. Care-giving organizations such as OSSA, Medan Acts, and Mekdim provide care and support services for PLHIV in two ways. Firstly, they provide care and support for bed ridden patients; this is a family centered support which includes provision of food, financial, medical and psychosocial support. They provide training for volunteers and for the families of PLHIV on how to give care and support at home. The second type is the care and support for individuals who are not acutely sick, mainly supporting involvement in IGAs.

Home based care is delivered by volunteers and primary care givers. Before engaging volunteers in HBC, care-giving organizations provided the volunteers training on: HIV, STI and TB/HIV related symptoms, communication skills with clients, provision of care for a bed-ridden client, assessing the felt needs of a client, prevention of bedsores, preparation of the corpse for burial or embalming without any fear, and conducting community conversations during coffee ceremonies. A volunteer could visit a beneficiary twice a week. He/she interacts with primary care-givers as they do with beneficiaries. Volunteers create awareness in the community on PMTCT and VCT while doing their HBC activities. Moreover, the volunteers use coffee ceremonies as opportunities for demonstrating condom use, educating the importance of VCT and enrolment and adherence to ART. The support to OVCs included the following, according to the national guideline for care and support on OVCs:

- (1). Nutritional support.
- (2). Medical care.
- (3). Educational support.
- (4). Psychosocial support.
- (5). Legal support and protection.
- (6). Household economic strengthening.
- (7). Vocational training.

In addition, some organizations provide informal education programs and link children with the appropriate organizations for legal protection of children and women. All orphans in the community get support regardless of their HIV status. Care-giver organizations also provide training for PLHIV on IGA skills. In addition, the organizations provide PLHIV with material and financial support.

Moreover, these organizations follow up on PLHIV to determine how they are managing the money given for IGAs. Others cover the cost of house rent and construction of houses for PLHIV in collaboration with the kebele administration and Idirs. Yet other organizations cover medical expenses of their beneficiaries, including cost of transportation to and from the health facility. There is also an NGO called BIGA, which facilitates post-delivery home care where HIV positive pregnant women can stay for two months after they give birth. The informants of the validation interviews implied that CHBC programs (mainly run by NGOs) "have done a lot in taking care of the needs of PLHI in the early days and will keep on doing so in areas of treatment adherence and health information provision, defaulter tracing, promotion of positive and healthy living and prevention". It was also indicated that organizations such as Mekidim Ethiopia do have their own ART clinics to provide treatment services to their clients.

The community facilitates the provision of HBC services. Members of the community are involved in activities such as identifying needy people (needy elders, needy disabled people and so on), PLHIV and OVCs. The government health extension workers (HEWs) in the kebeles are responsible for identifying individuals who are eligible for enrolment in care and support organizations while conducting their routine house to house visits. They then link the potential beneficiaries with the organizations providing care and support services. They also refer PLHIV for clinical matters to nurses at the health centres. Religious organizations are actively involved in providing spiritual counselling to clients in need of the services.

The Ethiopian Interfaith Forum for Development Dialogue and Action (EIFDDA), an umbrella organization for faith-based organizations, has programs such as: an OVC program, care and support program for PLHIVs, home based care and PMTCT program, emergency nutrition program, infant feeding practice program and extended program of immunization (EPI). Looking into governmental entities involved in care and support, it can safely be concluded that both the health and other sectors take some share at some point. While the FMOH mainly concentrates on clinical aspects of HIV/AIDS prevention and control activities, Regional Health Bureaus (RHBs), Zonal Health Departments (ZHDs) and Woreda Health Office (WrHOs) work closely with care and support organizations in selection of project sites, capacity building and reporting of activities. The WrHO

regularly receives activity reports from all health projects in the woreda (district). Public health facilities (hospitals and health centres) accept referral of cases from care and support organizations (although there is no formally established system to do so) and they also connect people who test positive for HIV with care and support organizations if the client is willing.

Moreover, the volunteers take clients to the health facility if the conditions of the patient get worse while on treatment at home. The selection of beneficiaries is done² in collaboration with kebele/village leaders of the government structures. The government officials at village level also work with Idir leaders in the process of selection. Associations of PLHIV, such as Kuntsu PLHIV association also work on awareness creation activities among women living with HIV. Idirs also help OVC's in providing educational material support for students like uniforms and in involving PLHIV in IGA's. Youth associations, women's associations and Anti-AIDS clubs also work on prevention activities such as raising young people's awareness, distribution of condoms and awareness creation leaflets.

They are working on awareness creation activities in the form of campaigns on the issue of prevention of mother to child transmission of HIV (PMTCT) in collaboration with health offices. HIV/AIDS prevention and control activities carried out by health care institutions include: individual-based health education activities, provider initiated counselling and testing service in all out patient departments, mobile VCT services, outreaches in colleges, schools and in the community, and distribution of condoms. In the case of treatment services for PLHIV, ART services are largely limited to the government health facilities.

The current contribution of care-givers in the ART services in the country is the promotion of enrolment and adherence. The care-givers remind the clients to take medications timely. Some of them visit the client two times daily to make sure that the clients take their medications. They also take the clients to the hospital when they need medical attention as in the case of treatment of opportunistic infections.

The care-givers collect the medications from the health facilities in cases where clients are too sick to come to the facilities. However, most of the study respondents doubt if the volunteers can handle the responsibility of providing ART themselves. None of the participants thought that this is a possibility in Ethiopia given the fact that the MOH policy does not allow this level of devolution. Hospitals provide food for malnourished HIV positive adults (FBP). ART adherence is being

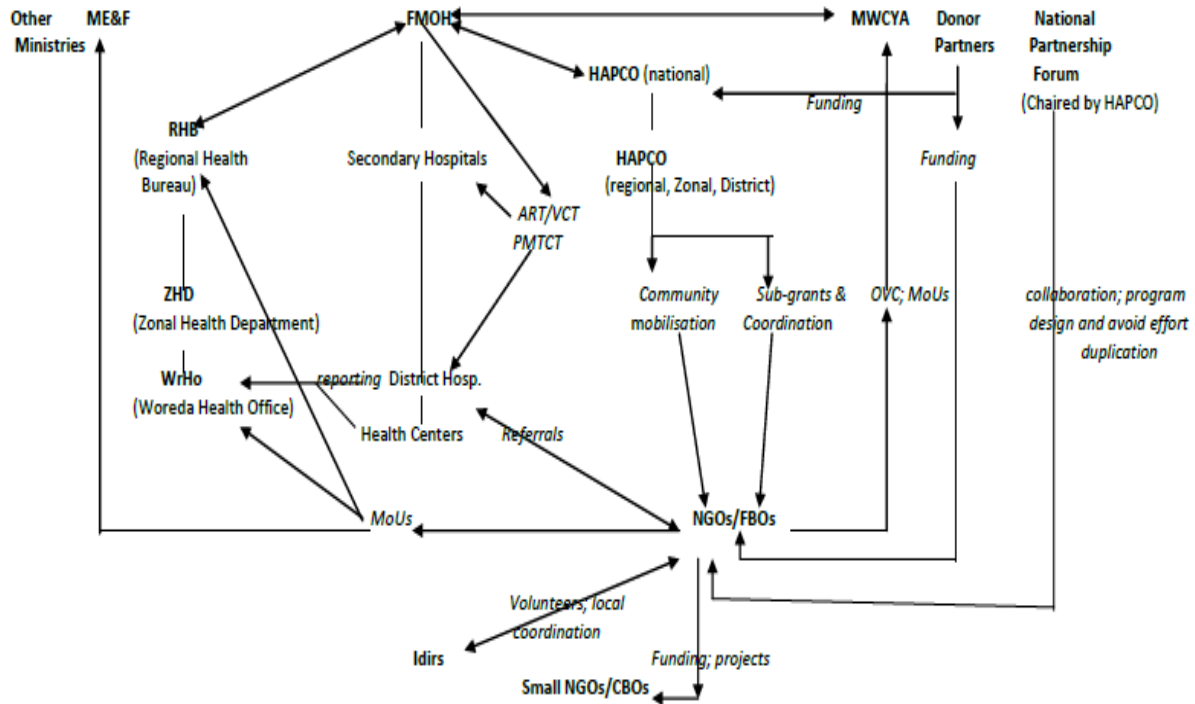
monitored through adherence supporters assigned by NGOs at the hospitals. Adherence supporters/promoters are HIV positive individuals on ART themselves. They give counselling on ART adherence, condom use and positive living to reduce the risk of HIV transmission in the community.

The major role of HEWs in relation to ART is identifying bedridden patients they may find during their house to house visits and refer him/her to the health centre. Once the person is on ART, they follow the person to ensure proper use of the medications. If the patient is bedridden, they give the drugs according to the schedule if there are no family members to do so. They also collect the drugs for the clients from health institutions if the person is unable to do so. As such the HEW's role in ART services is very similar to the activities carried out by the community volunteers functioning under the care-giving organizations. However, participants of the FGD with volunteers concluded that the HEWs of the rural kebeles are barely involved in HIV/AIDS activities since they are already intensely occupied by other activities. It was also noted that the HEWs in the rural areas do not provide counselling services, follow up of adherence to ART and tracing ART defaulters, although they perform HIV testing. Urban HEWs (nurses by training) help in identifying women and children who have not disclosed their HIV positive status to any organization during their house to house visits.

Moreover, in cities like Jimma, Addis Ababa and Hawassa, the HEWs are involved in defaulter tracing and promotion of adherence to ART services. Schools (mainly public) are also working on facilitating NGO support to OVCs (education materials, food and money). They facilitate IGA/small businesses for OVC students by availing different materials. In schools, there are also HIV/AIDS prevention and control programs such as awareness creation activities, peer education, life skill training and student conversation programs. At the beginning, care and support organizations were providing food items, cash and cost of medical care to clients.

However, the amount of food items and cash provided declined gradually and stopped totally with enrolment of clients in IGAs during 2010. When IGA first initiated, initial capitals were directly given to a self-support group which is formed by the clients. Currently however, the self-support group is linked with the micro-finance enterprise through which they receive their initial capital. This arrangement was considered to be more successful than the earlier one. The following figure depicts the various actors of care and support services for PLHIV in the Ethiopian context (Figure 1). The interaction of the actors indicated in this figure is also informed by the findings of the mapping exercises conducted by the community volunteers and community representatives. The figure depicts all the groups or organizations involved in care and support activities in Ethiopia. The roles and the names of specific organizations in each of the categories are given in the table to follow (Table 2). The figure

² Health extension workers (HEWs) are government employed health cadres who staff the health posts in each of the kebeles. They receive training of one year duration in several vocational schools throughout the country. The health post is the first point of contact between the Primary Health Care system and the community. The HEWs conduct mainly preventive activities together with treatment of childhood fever, diarrhoea and pneumonia. They are expected to spend 75% of their time in house to house visits.



Notes

- HAPCO currently works mainly on care and support not clinical matters
- Report from all the health facilities flow to the RHB through the WrHO and ZHD
- HAPCO is not separately organized in some regional states (e.g Oromia)
- National partnership forum has NGOs and GOs working in care and support as its members

Figure 1. Relationship between actors of care and support services for PLHIV in Ethiopia. ME&F = Ministry of economy and finance; FMOH = federal ministry of health; HAPCO = HIV AIDS prevention and control office; ART = antiretroviral therapy; VCT = voluntary counseling and testing; MWCYA = ministry of women, children and youth affairs; OVC = orphans and vulnerable children; NGOs = non-governmental organizations; CBOs = community based organizations; MoU = memorandum of understanding; Source: CAN multi-country research synthesis report (CAN, 2013).

above provides a reflection of the main actors of care and support of PLHIV in Ethiopia. It is shown that from the government side, the FMOH, HAPCO and other sectors (Ministry of Finance and Economic Development and Women, Children and Youth Affairs) play thorough roles related to their offices at different levels. NGOs and FBOs are shown to be at the heart of the community care programs of the country. But it has to be noted that these organizations receive support from the government, donors and the community to discharge their responsibilities (Figure 1).

Challenges and the way forward

It was noted that the resources available to the care and support programs is far less than the need of PLHIV. This is due to the fact that some of the care-giving organizations phased out their community care projects after the global fund and other funds supporting their projects ceased.

Monitoring and evaluation of care and support activities in the country by the governmental structure was considered to be minimal. The multi-sectoral response office was considered to be just a means of crisis management with little contribution in the coordination of HIV/AIDS related activities. Lack of follow up on the activities initiated by the care-giving organizations by the government health system (when the projects phased out) was also identified as a challenge. As reported by the participants, there is a lack of treatment options for OIs at the health facilities. Although the FMOH claimed that it has purchased the drugs, the drugs are not always available at the local clinics. Furthermore, some of the drugs that are specially purchased for OIs are used in clinics to treat other conditions and this contributes to the shortage. Currently, although accessibility of ART to people in need of the service is limited, it is very clear that there are no moves towards the devolution of ART in Ethiopia. Informants felt that the only feasible opportunity for devolution of ART to the community level is to make use of the already deployed HEWs.

Table 2. Actors and their roles in care and support of PLHIV in Ethiopia, April 2012.

Type of organization	Name of organization	Roles
Civil society organizations	Community based organizations (e.g. Idir)	Identification of volunteers. Advocate for minimizing stigma and discrimination. Creating awareness among community members.
	Kebele youth and women associations	
	Teachers associations	
	Anti-AIDS clubs	
	Family members	
	PLHIV associations	
Non-governmental organizations (care-giving organizations)	Trade unions	Set selection criteria of volunteers. Identify volunteers with the community. Training of volunteers. Deployment of volunteers. Supervision of volunteers. Availing necessary resources to the volunteers (e.g. kits to care and support the patients). Reporting to government health offices and their donors.
	Organization for social services for AIDS (OSSA)	
	Mekidim Ethiopia	
	Medan acts	
	CARE Ethiopia	
	Save the Children	
	Hiwot integrated development association	
	Path international	
	Pact Ethiopia	
	World vision	
Community members	Missionaries of charity	Directly provide care for bedridden patients. Link patients to the health facilities with the help of their supervisors. Help patients on ART to be more adherent. Work in mitigating stigma and discrimination among the community. Advocate VCT.
	Family health international (FHI)	
	Primary care-givers (family members) Secondary care-givers (volunteer individuals who are positive or negative).	
Donors	ART promoters	Provision of resources for care-giving organizations. Financial and non-financial.
	USAID, Global fund, UNAIDS, PEPFAR, WFP, UNICEF, UNFPA, CDC, World child planned national, EDD-Germany, CIDA and SIM-Canada, European union.	
Sub-granting organizations	Network of positives (NEP+)	Receive funds from the donor organizations. Sub-grant care and support programs to be implemented by the care-giving organizations. Receive financial reports from the care-giving organizations.
	CCRDA	
	EIFDDA	
Government system	Federal HAPCO	Develop policies and guidelines. Oversee HIV/AIDS prevention and control efforts. Accept patients referred from the care and support organizations. Connect HIV positive individuals with the care and support organizations.
	National HIV/AIDS council	
	HAPCO (federal, regional and district)	
	Federal ministry of health	
	Hospitals	
	Health posts (Health extension workers)	
	Regional health bureau	
	Zonal health department	
	Woreda/town health offices	
Other sector offices (Ministry of women, children and youth affairs, Ministry of education, Ministry of		

Table 2. Cont'd.

	labour and social affairs etc).	
Faith based organizations	<p>Ethiopian Kalehiwot church development department</p> <p>Ethiopian orthodox church - development and inter-church aid commission (EOC-DICAC)</p> <p>The Ethiopian Islamic affairs supreme council - Ethiopian muslims development agency (EIASC - EMDA)</p> <p>The Ethiopian evangelical church Mekaneyesus development and social service commission (EECMY - DASSC).</p>	<p>Establish organizations directly involved in care and support.</p> <p>Mobilize and allocate resources for care and support.</p> <p>Raise awareness of the community against stigma and discrimination.</p> <p>Raise awareness in the importance of adherence to treatment with ART.</p>
Forums	<p>NGO-forums</p> <p>National partnership forum (NPF)</p> <p>NGO-government forum</p> <p>Forum for faith based organizations, Idirs etc.</p>	<p>To create communications between the member organizations.</p> <p>Aims to avoid duplication of effort by the member organizations.</p>

Table 3. Summary of challenges faced by actors of community care and support programs.

Organization/party facing the challenge	Challenges
Care-giving organizations (NGO/FBO)	<p>Discrepancy between the load of beneficiaries and resources available.</p> <p>Interruption of funding (mainly from the Global Fund).</p> <p>Declining number of volunteers.</p> <p>Interruption of food support from WFP.</p> <p>Expectation of clients/dependency syndrome.</p> <p>Failure of clients to properly use the supports received.</p> <p>Unwillingness of local micro-financing institutions to take over IGAs.</p> <p>Failure to sustain activities initiated by the care-giving organizations on the part of the community and the government.</p> <p>Slow decision making process and feedback on the part of the government.</p> <p>Over emphasis on clinical care by the government.</p> <p>Lack of means of transportation to remote districts.</p> <p>Unfair selection of beneficiaries.</p>
Government agencies	<p>Poor coordination (monitoring and follow up).</p> <p>Failure of NGOs to report.</p> <p>NGOs follow short term strategies without long lasting effects.</p> <p>Failure of NGOs to stick to the MoU during implementation.</p> <p>Inaccessibility of ART.</p>
Care-givers/volunteers	<p>Shortage of food support.</p> <p>Variable mood of clients.</p> <p>No more support from the care-giving organizations.</p> <p>Change in the address of the client.</p> <p>Having different sex from the client.</p> <p>Failure of clients/family members to cooperate.</p> <p>Stigma and discrimination of clients by health professionals and school mates.</p> <p>Husband may not allow volunteering.</p> <p>Too much burden when added on family and workplace responsibilities.</p> <p>Negative attitude of community members.</p> <p>Poor record keeping at the health facilities.</p> <p>Long waiting time at the health facilities.</p>

Table 3. Cont'd.

Health facilities	<p>Difficulty of convincing clients to disclose ones status to partner. Failure of primary caregivers to take care of a family member.</p> <p>Poor medication adherence. High dropout rate. Shortage of trained health human power. High cost of training. Lack of drugs to treat opportunistic infections. Failure of CD4 counter machine.</p>
-------------------	---

Source: (Woldie et al., 2013).

This will definitely require training the HEWs to take the responsibility. In some parts of the country, the community has not developed sense of ownership for care and support programs. This was said to be particularly true in areas where the kebele administration and Idirs are not cooperative to the care-giving organizations. The selection of beneficiaries was also identified as one of the challenges encountered. Organizations cannot support everyone, so a selection needs to be made. Especially in care and support projects for OVC, this becomes very challenging, according to what several key informants mentioned. Table 3 provides a summary of the challenges faced by actors of community care and support programs in Ethiopia as voiced by representatives of the actors. Some of the solutions proposed to solve challenges regarding resource scarcity for treatment and care were the need for community mobilization and capacity building of local Faith Based Organizations (FBOs).

It was identified that care-giving organizations should create direct linkages with local FBOs, but not directly with the beneficiaries. For example, EIFDDA aims to have no direct contact with PLHIV, but give responsibility to local organizations, such as Idirs, churches, mosques and local women associations. A reason for this is that the local organizations have existed for centuries despite change of governments which contributes for better sustainability. Several key informants agreed that the focus should be on economic strengthening and empowerment of PLHIV and their families through the creation of income generating projects, provision of vocational training, and support for those who discontinue school, or support at workplace so that they will be competitive and productive. With regard to increasing access to ART services, the provide the service. To this end, the Sidama Zonal Health Department (ZHD) is looking for funds to train health professionals on the provision of ART services.

The feared future challenges in the provision of ART include drug resistance, interruption of donor support including ART drug provision, lack of drugs to treat

opportunistic infections, absence of home based care for PLHIV and difficulty in defaulter tracing in the absence of the current volunteers supported by the NGOs. Another concern at the ART clinics in the hospitals was the high flows of clients despite the fact that services are decentralized to the health centres. Addressing this particular problem requires tackling the fear of stigma and discrimination as clients tend to opt for services outside their locality.

Conclusion

Currently, the main problem of PLHIV in Ethiopia is to have access to adequate food which is required while taking their regular medications (Aantjes and Jerene, 2010). Other support needs are socioeconomic support through involvement in IGAs, support for school fee and educational materials for OVC and psychosocial support to clients and family members. Similar findings were also recorded in Zambia and Malawi (CAN, 2013). We have also confirmed that the emphasis in patient needs has now clearly shifted from 'basic nursing care in the home to livelihood support' (Aantjes and Jerene, 2010). The need for clinical and health care needs is evidently palpable. The services provided to PLHIV are categorized into 'clinical' and non-clinical. Initially, care and support services ('non-clinical') in Ethiopia were mainly delivered by NGOs (Aantjes and Jerene, 2010). Later on, the involvement of the government through provision of opportunity for involvement in IGAs and food support by the health offices and health facilities at different levels was indicated. Services provided to PLHIV and their families are psychosocial, economic, material and nutritional support services, and clinical care mainly provided by the MOH facilities (VCT for early detection, treatment for opportunistic infections (OIs), ART services, and PMTCT). Major actors of care and support of PLHIV in Ethiopia are the community (primary and secondary care-givers, ART promoters and civil society organizations), care-giving organizations (mainly

NGOs), government structures (the health system and other sector offices), religious organizations, donors, sub-granting organizations and forums of these organizations.

Conflict of Interest

The authors have not declared any conflict of interest.

ACKNOWLEDGEMENTS

We are thankful to Care-givers Action Network (CAN), Cordaid and UNAIDS for initiating and funding this research project. We would also like to thank all managers, program staff, clients, community volunteers and community representatives who were quite cooperative during data collection. The support and guidance we received during data collection from the Advisory Board (AB), particularly Mr Getnet Kassahun who was the coordinator of the AB, was also remarkable. We also thank Caroline Aantjes and Tim Quinlan who had been of great help in the entire research process.

Abbreviations: **AIDS**, Acquired immunodeficiency syndrome; **ART**, antiretroviral therapy; **BMI**, body mass index; **CAN**, caregivers action network; **CHBC**, community home based care; **EIFDDA**, ethiopian interfaith forum for development dialogue and action; **FGD**, focus group discussion; **FHAPCO**, federal hiv/aids prevention and control office; **FHI**, family health international; **FMoH**, federal ministry of health; **HAPCO**, hiv/aids prevention and control office; **HBC**, home based care; **HEW**, health extension workers; **HIV**, human immunodeficiency virus; **IGA**, income generating activities; **JHU**, john hopkins university; **MoWCYA**, ministry of women, children and youth affairs, **NEP+**, network of networks of hiv positives; **NGO**, non-governmental organizations; **OSSA**, organization for social services for aids; **OVC**, orphan and vulnerable children; **PLHIV**, people living with hiv; **PMTCT**, prevention of mother to child transmission; **STI**, sexually transmitted infection; **TB**, tuberculosis; **TBA**, traditional birth attendant; **UNAIDS**, joint united nations program on hiv/aids; **USAID**, united states agency for international development; **VCT**, voluntary counselling and testing.

REFERENCES

- Aantjes C, Jerene D (2010). Home Based Care Scan Ethiopia. Leusden, the Netherlands.
- Adedigba MA, Ogunbodede E, Jeboda S and Naidoo S (2008). Self-Perceived and Unmet General Health Need among PLWHA in Nigeria. *East Afr. J. Public Health* 5(3):199-204.
- AHOPE (African HIV Orphans: Project Embrace) (2005). Ethiopia and HIV/AIDS. Available at: <https://www.ahopeforchildren.org/the-hope/>
- Alison W, Fabian C, Nicola S, Ade F (2010). Delivering comprehensive home-based care programmes for HIV: a review of lessons learned and challenges ahead in the era of antiretroviral therapy. *Health Policy Plan.* 25(5):352-362.
- Assefa Y, Jerene D, Lulseged S, Ooms G, Van Damme W (2009). Rapid Scale-Up of Antiretroviral Treatment in Ethiopia: Successes and System-Wide Effects. *PLoS Med.* 6(4):e1000056.
- Boryc K, Anastario MP, Dann G, Chi B, Cicutelli B, Steilen M, Gordon-Boyle K, Singh S, Morris M (2010). A Needs Assessment of Clients with HIV in a Home-Based Care Programme in Guyana. *Public Health Nurs.* 27(6):482-491.
- Caregivers Action Network (CAN) (2013). Multi-country research on community caregivers: the backbone for accessible care and support – synthesis report: The Caregivers Action Network.
- Feyissa GT, Abebe L, Girma E, Woldie M (2012). Stigma and discrimination against people living with HIV by healthcare providers in Jimma zone, Southwest Ethiopia. *BMC Public Health* 12:522.
- Hailu A, Stuer F (2002). 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.
- Kabore I, Bloem J, Etheredge G (2010). The Effect of Community-Based Support Services on Clinical Efficacy and Health-Related Quality of Life in HIV/AIDS Patients in Resource-Limited Settings in Sub-Saharan Africa. *AIDS Patient Care STDs* 24(9):581-594.
- Mohammad N, Gikonyo J (2005). Operational Challenges Community Home Based Care (CHBC) for PLWHA in Multi-Country HIV/AIDS Programs (MAP) for Sub-Saharan Africa, AIDS Campaign Team for Africa (ACTAfrica); Africa Region Working Paper Series, 2005, No.88.
- Ncama PB (2005). Models of Community/Home-Based Care for People Living With HIV/AIDS in Southern Africa. *J. Assoc. Nurs. AIDS Care* 16(3):33-40.
- UNAIDS (2000). Report on the global HIV/AIDS epidemic. June, 2000.
- Woldie M, Morankar S (2013). Multi-country research on community caregivers: the backbone of accessible care and support - Ethiopia report. The Caregivers Action Network.
- World Health Organization (WHO) (2013). Global update on HIV treatment 2013: results, impact and opportunities: WHO report in partnership with UNICEF and UNAIDS.