

A Study on Challenges of People Living with HIV/AIDS (PLWHA) with a Special Reference to Gondar Town, North Western Ethiopia

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Abstract: *Now –a- days, Community Home Based Care plays a vital role in the care of People Living with HIV/AIDS. Most community members performs different role in relation to care and support of People Living with HIV/AIDS. Yet, little is known about the practical activities they perform to People Living with HIV/AIDS and the response is not well documented. To implement Community Home Based Care program for People Living with HIV/AIDS efficiently and affectivity it is necessary to assess the community response in care and support of People Living with HIV/AIDS. In depth interviews and Focus Group Discussions were conducted with People Living with HIV/AIDS and Volunteer home care gi-vers in order to know the problems and challenges faced by them. The findings of the study revealed that People Living with HIV/AIDS have a variety of challenges in their every walk of life. At the heart of all their challenges lies poverty, although lack of housing and food were identified as major problems. As noted in the findings the over whelming poverty, stigma and abuse, lack of transportation, lack of proper treatment, lack of consciousness, sense of dependency were indicated as major challenges that affect the provision of care and support to People Living with HIV/AIDS in the community.*

Introduction

The impact of HIV/AIDS goes beyond public health concern because it primarily affects adult populations in the productive and reproductive age groups and, in its pandemic stage undermines the social and economic structures of developing countries (MOH, 2000). With an estimated 1.3 million people living with HIV/AIDS and a national prevalence rate of 4.4%, Ethiopia is one of the hardest hit countries by HIV/AIDS epidemic (MOH, 2006). In the global scale, Ethiopia hosts the fifth largest number of people living with HIV/AIDS. The estimated HIV prevalence in the Amhara National regional state where the study zone is located was about 11% and the prevalence in urban and rural areas of Gondar town was 14% and 8% respectively (MOH, 2004). As part of the response against the epidemic, different programs are being carried out in the country. One of the

most important programs that should be examined in this regard is home based care. Home based care plays a vital role in the care of millions of AIDS patients in Sub Saharan Africa where over burdened medical and welfare services are not sufficient to cope with the demands of the epidemic. Home based care programs for People Living with HIV/AIDS (PLWHA) were implemented in different African countries after the inception of the epidemic (MOH, 2001).

The delivery of organized basic medical and psychological support for AIDS patients in their home has several advantages for patients and their families. These advantages include reduced hospital and transport costs and reduced isolation from family and friends (Max et al, 2002). In addition, admission of patients that are likely to stay in hospital for long duration has been a challenge to the already constrained health service in developing countries, especially those in sub

Saharan Africa. On the other hand, patients and families may not be able to afford the long stay in hospital setting both in psycho social and economic terms. Thus, provision of a well organized home care has been adopted by many different countries as a strategy to alleviate these problems by ensuring the continuum of care (MOH, 2001). Currently, grass roots participation, community mobilization and multi sectoral partnerships form articles of faith in response to HIV/AIDS in Africa and world-wide (Campbell, 2004). Therefore, this research attempts to assess the extent of the community response in the provision of care and support for PLWHA in the study area. It looks at the problems and needs of PLWHA, challenges faced by the community in the process of providing care and support for PLWHA and opportunities in the target locality for effective intervention in the future.

Literature Review

The global HIV pandemic has had a profound, multi-sectoral impact on the structure of many nations, affecting their development and economic growth, communities, households and individuals. In many countries AIDS has been identified as a serious challenge to development with both short and long term economic effects (NHAPCO, 2007). HIV/AIDS is no longer just a medical but a socio-economic and development issue with a wide ranging and complex economic, social and cultural implications. In Ethiopia the number of new infections was 128,922 (353 per day) including 30,338 HIV positive births. AIDS related death in Ethiopia are estimated at 134,450 (368 per day) including 20,929 children 0-14 years (MOH/NHAPCO, 2006). The HIV/AIDS pandemic in Ethiopia is adversely impacting the country's development in general. According to the sixth report AIDS in Ethiopia (2006), at the structural

level, HIV/AIDS is affecting various sectors of the nation in addition to the damages it is incurring on families and communities. Because HIV/AIDS often hits the working age population the hardest, the workforce of many nations has been affected, as skilled workers are lost to the epidemic. The loss of skilled workers in turn affects nation's ability to respond to the epidemic (NHAPCO, 2007). In the context of Ethiopia, HIV/AIDS is increasingly affecting the agricultural sector, economically the most important sector, accounting for an average of 48% of GDP, and 90% of exports. The fact that HIV prevalence is increasing in rural areas where 85% of the 69 million Ethiopians live, has become major concern to the development efforts in the country (ARC, 2005).

The epidemic is also affecting health care and quality because increasing health care resources and facilities are used to treat PLWHA. The severely constrained health care system is also being further challenged by the HIV pandemic. According to the ARC (2005), about 40% to 60% of hospital beds in Ethiopia were occupied by AIDS patients in 2001. The increased number of patients seeking medical care for HIV/AIDS related diseases such as TB and other opportunist infections is stifling the already limited health care system in Ethiopia. Home based care programs for PLWHA started in North America and Europe when it became clear that hospital care was too expensive and that family and other care givers found it difficult to cope on their own with the demanding nature of caring for PLWHA (Spier and Edward, 1990). In most African countries, there are now well developed home based care programs and systems, although access to these programs is still not universal (Uys and Cameroon, 2003). Community based care, specifically in relation to HIV/AIDS includes any aspect of care along a continuum of illness, from the time a person is

infected through to terminal illness. Care may continue in the form of counseling after the patients' death for those who are left behind (USAID, 2002). Community care is usually based outside formal health facilities, but is built on partnerships with formal government sectors, such as health, welfare and development sectors.

Research Design and Methodology

Statement of the problem

The problem of HIV/ AIDS remains complex and incurable. It is incurring serious negative repercussions on individuals, communities and nations worldwide. The rate of new HIV infections also continues to climb every year. Prevalence and new infection rates are increasing alarmingly, making the issue of primary concern among many nations. The epidemic is reversing social and development gains, deepening poverty, challenging the national priority of expanding and maintaining essential services and reducing labor and intellectual productivity (NHAPCO, 2003). In Ethiopia, the single point HIV prevalence estimate in 2007 was 2.1% of which 1.7 % among males and 2.6% among females. The estimated prevalence in urban areas is 7.7% and 0.9% in rural areas (MOH, 2006). As the HIV/AIDS epidemic continues to grow many organizations and communities are now considering a more programmatic approach. Countries are looking for scaled up responses and nations wide strategies for Community Home Based Care (CHBC) (WHO, 2002). CHBC focuses care within the home and is therefore considered to be an alternative to traditional institutionalized care. This is because the increasing number of patients hospitalized for an extended period of time has stretched the resources of the health care system. Discharging patients into the home care program will allow shorter stay of HIV/AIDS

patients in hospitals, making more beds available for other patients and reducing costs to the institution. So far, several attempts have been made to respond to the HIV/AIDS pandemic in Ethiopia. Immediately after the first report of laboratory confirmed HIV/AIDS cases, the government of Ethiopia initiated the responses.

In Ethiopia, HBC programs are initiated and operated in a few areas of the country by adopting it as a strategy from other African countries. However, the practice has been diverse, not following any standards in terms of quality of care even if the ministry of health has developed national guide line on CHBC for PLWHA to help organize the service (MOH, 2001). In the Ethiopian context, various governmental, non-governmental, community based and faith based organizations are implementing programs related to care and support of PLWHA. Specifically, communities' are playing an active role in the provision of care and support for PLWHA and improving the quality life of PLWHA. Moreover, the need of community mobilization and motivation were suggested as a means to reduce stigma and discrimination besides awareness raising programs to make the community participate in the Home Based Care (HBC) program (Africa development forum, 2000).

Currently, we see some communities which provide care and support for PLWHA and their families. However, we don't have clear and systematized information about the specific role of the community in care and support of PLWHA. Nor do we have information on the challenges and the constraints community are facing while providing services. In other words, the community response in care and support of PLWHA is not well documented and developed using systematic research. So we don't exactly know what the practical response of the community is. In addition,

we don't clearly know the current problems and challenges of PLWHA, and the kinds of services being offered to them. Given the limited human, financial and material resources to support HIV/AIDS related initiatives, this would in turn challenge interventions in relation to HIV/AIDS prevention and control. Therefore, this research is aimed to understand problems and challenges encountered while providing the services in the target community selected for the study.

Objectives of the study

The primary objective of the study is to understand the challenges and problems encountered by the PLWHA in order to get required services to mitigate the problem. The specific objectives of the study are: to

- (i) identify coping mechanisms used by PLWHA to address their problems;
- (ii) identify the challenges communities are facing in rendering services to PLWHA; and
- (iii) suggest some required recommendations to mitigate the problems and challenges faced by PLWHA.

Description of the study area

The study was conducted in North Gondar administrative zone, Gondar town. North Gondar administrative zone is divided into 18 woredas. The town of Gondar is divided into 21 kebeles. The particular study site is the town of Gondar which is located 742 kms north of Addis Ababa. According to information from the city municipality, the inhabitants of the town are predominantly from the Amhara ethnic group, with some Tigre. The town is one of the fastest growing cities in the country. It

has a total population of more than 200,000 and is a center of business and tourism. Currently, the town is strategically important to connect the country with Sudan. Although the prevalence of HIV/AIDS infection is high throughout the region, the town is underserved by organizations involved in HIV/AIDS prevention and control interventions. According to the HIV/AIDS Prevention and Control Office of the town (HAPPCO), an estimated number of more than 2500 people are currently living with HIV/AIDS. The stigma and discrimination related to HIV/AIDS is also high. Some local projects funded by external donors provide care and support to PLWHA. Community 'Idirs', 'Senbetes', 'Jemias' and PLWHA associations are some of the community institutions which provide care and support to PLWHA, as indicated by official of zonal HAPCO.

Population of the Study

The populations for this study are PLWHA living in Gondar town and their caregivers. In addition, various relevant personnel and positions holders were involved as primary sources of data for the research. It includes PLWHA(24) in the target locality, volunteer care and support providers(8); relevant government official(1), non-government organizations working towards addressing the issue in the locality(2), leaders of CBOs(2) and FBOs(1).

Selection of Participants

Participants for the study were selected in collaboration with the Frehiwot association of PLWHA residing in the town. The Frehiwot association is the only association of people living with HIV/AIDS in Gondar town. Hence, for the selection of PLWHA who would participate in the interviews, snow ball technique was applied with the help of the program coordinator of the

association. The same method was employed to select volunteer care givers for the interview. As a qualitative research study, the decision on how many people to interview rested on reaching data saturation or redundancy (Monette, R, 1998). The researcher believed that data saturation was achieved because the same issues were being repeated by the participants in the course of the interview. Therefore, it appeared that twenty four (24) in depth interviews with PLWHA and eight (8) in depth interviews with individual Volunteer home care (VHC) givers provided enough data to be confident that the analysis would adequately represent the experiences and perceptions of the research respondents.

Participants for the focus group discussions were also selected with the help of the program coordinator of Frehiwot association. Participants for the Focus Group Discussions (FGD) included PLWHA and care and support providers. Key informants were selected from the Association of People Living with HIV/AIDS, zonal HIV/AIDS Prevention and Control Office (HAPCO), woreda HAPCO and NGOs, CBOs and FBOs working on the issue. In all of these, verbal consent of participants to participate in the research was obtained and confidentiality is also promised.

Data collection

Interviews and FGD were employed as primary sources of data for the research. Relevant secondary sources were also reviewed to trace the background of care in Gondar town and also to compliment and validate the findings.

Data collection tools

Interviews : Six interview guides were prepared for the study. Thirty eight interviewees participated in the research. Especially PLWHA as an important

source of data were not willing to be tape recorded. Thus, the researcher took written notes on the interviews.

Data processing and analysis

To start with the rough notes of the interview were converted into organized notes. The information collected using the above data collection techniques was analyzed using thematic way which examines each record in order to come up with patterns or themes that can accommodate the data gathered in to specific categories. In the process of organizing the data, the researcher used codes under each category in order to easily understand the expressions of respondents. Finally, the information was brought together by triangulation method of content analysis. In other words, the information obtained from in depth interview, key informant interview and focus group discussions and data from field observation were triangulated and presented under each category.

Limitations of the study

Data for the study was collected only from one urban woreda out of eighteen woredas in North Gondar. The research would have been more revealing if data could be collected from both rural and urban settings which would have made comparison among these groups possible. However, as an area which needs to be further explored, the researcher believes that the study would serve as a spring board to conduct further research on different aspects of the issue. The research is limited to one woreda due to of time and financial constraints. Specifically, the limited time the researcher had to finalize the research seriously challenged the study as he was engaged in fulfilling the requirements of other courses as well.

Results and Discussion

The following table shows the socio-demographic variables of PLWHA respondents for the study. As shown in table 1, out of the total 24 PLWHA respondents who have participated in the in depth interview, 14, were females and 10 were males. With regard to the marital status of the respondents, 12 of them were widowed, while one quarter (6) of them were

Table 1: Socio-Demographic Characteristics of PLWHA

Socio Demographic variable	Category	Number
Sex	Male	10
	Female	14
Marital status	Single	4
	Married	6
	Widowed	12
	Divorced	2
Ethnicity	Amhara	22
	Tigre	2
Religion	Orthodox Christian	22
	Muslim	2

Level of education	Illiterate	6
	Primary	12
	Secondary school	4
	12 & above	2
Employment	Employed	6
	Unemployed	18

Source: Primary data

Currently married. On the other hand, 4 are single and the rest 2 are divorced. When we look at the religious affiliation of the interviewees, 22 of them, reported to belong to Orthodox Christianity, while 8.3% are Muslim. While the great majority, (22), reported to belong to the Amhara ethnic group, the rest 2 reported to belong to the Tigre ethnic group. As to the educational status of the respondents, half of them (12) of the respondents have attended primary school education, while 6 of them reported to be illiterate while attended secondary school or above were about one fourth of the total. Regarding the employment status of the respondents, 18 are unemployed, while the rest 6 are employed.

Challenges in the Provision of Care and Support for PLWHA

The data for this study revealed some possible obstacles in the process of provision of care and support to PLWHA.

Poverty

One of the most pervasive themes throughout this research was the experience of poverty. The majority of (VHC givers and key informants) explained that most of their patients receiving home

care and support services are very poor. They are experiencing profound shortages problems of basic necessities in their households. As a result, the home based care service has been severely compromised. Most of the VHC givers respondents reported that they had confusion and frustration due to shortages as well as absence of house materials and the financial problems of the PLWHA that hinders them from accomplishing what they planned to do for the patients. Besides, it was indicated by most VHC givers that there is over expectation of the services provided by the patients themselves. As one VHC giver reported

Whenever I visit my patients, the usual question is “what did you bring to me today”. This basically arose from the overwhelming poverty they are wallowing in.

Usually the cost for medical care, drugs, medical supplies and transportation had to be borne by the family of the sick person themselves. Consequently, families use the little money they might have to provide for these services. In most instances, the sick person himself/herself was the sole provider of income for the household. In such cases, families become destitute as they try to provide adequate care to the sick person. Gradual effect of these would be that they eventually became hopeless, uncooperative and disinterested to participating in care of patients. One VHC giver reported that:

Our patients are poor, helpless and weak. It is very difficult to provide the services as needed. . Therefore, patients should be supported with adequate food and household utensils. I have a patient who lived with his families; the family sold all their household utensils to cover all the necessities of the patient. When they have reached to a point where they have sold everything at home,

they finally gave up and had to see the patient die while they could have prolonged his life had they been found in a better financial capacity.

Stigma and Discrimination

In this study, stigma was also reported to lead to discrimination, isolation, rejection and abuse. Some VHC providers reported that some people considered them as to be HIV positive themselves. Most others reported that many of their patients were stigmatized by their family and community members. “We really could not freely go and visit our patients”, said one caregiver in the focus group discussion held. In short, the perceived discrimination of the community and the self stigma of the patients themselves is reported to be a great barrier in the provision of care and support services to PLWHA.

In this regard one PLWHA indicated during the in-depth interview:

Due to fear of stigma and discrimination, I don't want to tell my neighbors about the kind of care and support I am being offered. They usually asked me the reason why my care giver visits me. I used to tell them as if she is my relative.

Lack of adequate transportation

The problem of transportation faced by volunteer caregivers is another challenge. To begin with, care givers only receive 50 birr /month as a transportation allowance from their organizations, which obviously is not enough to carry out the task effectively. What makes the matter worse is that when they reached the intended residence, they often find patients who need to be taken to health facilities for an urgent medical care. But as there is only one ambulance for 200,000 of the city population, taking these patients found in a critical

condition to a health facilities is usually difficult. Some of the VHC givers reported that they get financial support from their organizations for transportation during a home visit. However, they mentioned that the money is not given on time as well as it is not adequate. Because of this they are forced to travel long distances on foot to visit each patient. So they become physically weak, waste much time without giving practical care and gradually lose interest in voluntary service.

In addition, they reported that the access to health facilities was severely compromised due to lack of affordable or free transportation especially for those patients who have a financial problem. If patients and family members are unable to pay for transportation, they cannot reach even to the nearest health center available. As one VHC giver commented:

I know a severely ill patient who died due to lack of medical care in hospital. This was due to absence of transportation to take him to the health facilities.

Emphasized by the majority of the VHC givers is that the issue of affordable or free transport for the severely sick patients requires serious consideration by all concerned stakeholders in order to need to provide effective HBC for PLWHA. In line with this, PLWHA participants of the FGD stressed that, when they need to be seen by physicians at the health center and hospital, most of the time they used to face lack of transportation. Two PLWHA participants in the course of in-depth interview reported that they failed to reach health facilities while they were seriously sick due to lack of transportation.

Lack of proper Medical Treatment

The issue of transporting the patients at least to the nearest health institution is not the only problem.

There is also a serious problem of proper medical treatment in these health institutions. Many of the participants share the view that the lack of proper treatment has generally been a serious challenge. As one VHC giver explained it:

Some staff in the hospital does not care for the patients. They consider HIV/AIDS patients as hopeless and simply wasting resources. They also usually tell us that there is no need of admission for such patients. They give priority for the others. The heart of the patients would be broken when they hear such comments from people who should provide the most care in actual terms.

Similarly, PLWHA participants during the FGD indicated on the problem of treatment at the health institutions. As one PLWHA participated in the FGD explained:

For me it better to stay home than going to health facilities. You can see lots of problems there. Starting from admission to the whole process of treatment, we used to have different problems. It seems that hospital staffs are tired of providing treatment for us. This is particularly true of the nurses. They don't treat us properly. They would let us stay longer without having treatment. Most of the time the physicians simply prescribed medicines related to pain killing without conducting adequate diagnosis. Proper medical treatment for PLWHA is, therefore, one serious problem in need of urgent solution.

The wrong perception of community members

Another challenge for the care providers is the wrong perception of the community towards their voluntary support. According to the information from a key informant, some members of the community think that such supports have a political agenda on the side of the government in terms of

securing the support of the community. The other issue is that, some people think that the care givers are making a good deal of money out of the task they are performing. “The community perceives that we have some ulterior motives behind our supposed free care and support program”, said one VHC giver. Finally, many care givers also reported that people consider them to be HIV positive and subject them to the stigma and discrimination faced by their patients. Such misperceptions are not only held by community members only but also by families of the caregivers. Most of the caregivers reported that they are told to quit the volunteer work as it brings no economic reward. Most care givers are discouraged to go and help their patients as they themselves have economic problems to deal with. This way, voluntary care and support provision is by itself a demanding and challenging task for those involved in it.

Duplication of efforts

Duplication of activities among different organizations is another challenge reported by most key informants. Mahiberhiwot Ethiopia, OSSA, and CVM are some among others organizations providing care and support to PLWHA in Gondar town. However, they were working on similar issues and clients. For instance, it was observed that these organizations are providing food and material support to PLWHA living in similar kebeles for similar clients. Similarly, ‘idirs’, ‘senbetes’ and ‘jemias’ are also providing care and support for same clients. Thus, the activities of these organizations are usually seen to overlap. Key informants feel that several organizations target similar issues and clients, which eventually leads to the wastage of already limited resources.

Dependency Syndrome

Sense of dependency on the part of clients is also a major challenge noted by VHC givers during focus group discussion and key informant interview. VHC givers noted that patients mostly need financial and material support. However, they said that all clients demand care and support services regardless of their degree of illness. With the limited resources available to support these people, it would be difficult to provide care and support for all patients. Despite the fact that some patients could be able to work, there is a tendency for them to develop a dependency syndrome on the community and philanthropic organizations.

Conclusion and Recommendations: Across the world, the number of people and families living with HIV/AIDS who are in desperate need of care and support services is increasing dramatically. The study has revealed that PLWHA have more limited choices than even the other segments of the community to improve their economic status. Some of the challenges in the provision of care and support for PLWHA identified in the study include augmented poverty, stigma, discrimination, problems of transportation, lack of proper medical treatment, still underdeveloped awareness with regard to the problem, and dependency syndrome on the side of the victims. At the heart of these challenges is the problem of poverty. Socio economic problems mainly the shortage of basic necessities in the patient’s house was one factor that hinder the care and support provision for PLWHA. However many the current challenges may be, the findings have, on the other hand, shown that there are now more opportunities for the provision of enhanced care and support for PLWHAS. The changing attitude of the community towards PLWHA and HIV/AIDS, the existence of good policies and strategies and the commitment of government, NGOs, CBOs and FBOs are great

opportunities identified in the study in the provision of care and support.

Based on the findings of the study in the target locality and the documents reviewed on the issue, the researcher recommends the following points:

1. The local government should give due consideration to the housing problem of HIV/AIDS affected people;
2. To provide proper medical care to PLWHA, there is a need to sensitize the medical care providers at the health institutions.
3. There is a need to avail transportation facility to PLWHA who need to be taken to the health institutions by organizations working in the local community.
4. Local government bodies and NGOs working in the community should give major attention on the allotment of enough money to help the caregivers maintain their commitment that they cannot support themselves ever again.
5. In order to implement optimal HBC program for PLWHA, the need of all stakeholders' participation in the community is indispensable since HIV/AIDS is not just a medical problem but also a social, economic and developmental issue that requires a multi-disciplinary response.
6. Designing a separate policy and strategies of implementation on care and support endeavors for PLWHA

would be helpful to the effectiveness of related ventures;

7. Repeated and detailed researches taking larger sample size and covering more woredas in the locality would help narrow the knowledge gap in the area for more action and intervention to be taken;

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