

**ASSESSMENT OF COMMUNITY VOLUNTEERS HOME BASED CARE
FOR
PEOPLES LIVING WITH HIV/AIDS
IN ADAMA (NAZARETH) TOWN, ETHIOPIA.**

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List of abbreviations

AIDS : Acquired immuno-deficiency Syndrome

ART: Antiretroviral therapy

CBOs : Community based organizations

CVHBC: Community volunteer home based care

CHBC: Community home based care

CHWs: Community health workers

EMOH: Ethiopian ministry of health

FGDs: Focus group discussions

HAPCO: HIV/AIDS prevention and control office

HBC : Home Based Care

HC : Home Care

HIV : Human immuno-deficiency Virus

IEC: Information, education and communication

NGOs : Non-Governmental Organizations

PLWHA: People living with HIV/AIDS

PMTCT: Prevention of mother to child transmission

STIs : Sexually transmitted infections

TBAs: Traditional Birth Attendants

WHO: World Health Organization

VHC-givers: volunteer home caregivers

VCT: Voluntary counsel and test

BCC: Behavioral change and communication

Abstract

Background: Currently, HBC programs for PLWHA are implemented in different African countries after the inceptions of the epidemic. However, the designed HBC programs may differ from place to place, that means whether model of community/NGO-based initiative or Hospital-based initiative HBC programs. To implement CHBC program for PLWHA efficiently and effectively, it is necessary to assess the perceptions and contextual experience of home caregivers in the community.

Objective: It was to assess and explore the contextual based experience of CVHBC service for PLWHA in oromia region, Adama (Nazareth) town.

Methods: Using a qualitative method the perceptions, range of activities, and the major challenges in HBC were described in this study. In-depth interview and FGDs were conducted with VHC givers and their team leaders selected from the 'six' HBC-teams in the town. The selection of study-participants was purposive with the aim of obtaining knowledgeable and experienced individual VHC-givers from the team members.

Findings: The findings were described in three categories: perception of VHC givers to HBC, range of HBC activities, and challenges in HBC. The result showed that VHC givers perceived that HBC is a continuum of care that help PLWHA by providing basic care according to their needs in their home without any gap between health facilities and HBC. However, they performed a limited range of home care activities that were inadequate care. Further more, patients' poverty, lack of adequate resources, lack of adequate support; presence of stigma, rejection, and abuse; lack of training and supervision by health professional and for caregivers, and lack of health care infrastructures were indicated as the major factors that affect the provision of better quality home care.

Conclusion: In general, the HBC process in the study areas were indicated that it was unorganized and not coordinated, which means there was lack of professional support as well as lack of adequate materials and financial support besides the lack of all stakeholders' participations, lack of adequate HBC infrastructure and the absence of communications among the organizations. Further studies, however, are recommended for better understanding of these major challenging issues in HBC of PLWHA, using a combination of qualitative & quantitative research methods.

Introduction

Currently, home based care (HBC) programs for people living with HIV/AIDS (PLWHA) are implemented in different African countries after the inceptions of the epidemic. It is one of the current HIV/AIDS prevention and control strategies such as voluntary counseling and testing (VCT), management of sexual transmitted infections (STIs), information, education and communication (IEC/BCC), management of opportunistic infections, universal precautions and post- exposure prophylaxis, safe blood transfusion, anti-retroviral therapy (ART) and prevention of mother to child transmission (PMTCT), surveillance and research, care and support, and technical support to different sectors, including human rights (1).

The delivery of organized basic medical and psychological support for AIDS patients in their homes has several advantages for patients and families. These advantages include reduced hospital and transport costs and reduced isolation from family and friends (1, 2).

In addition, admission of patients that are likely to stay in hospital for long duration has been a challenge to the already constrained health services in developing countries, especially those in sub Saharan Africa. On the other hand, patients and families may not afford the long stay in hospital setting both in psychosocial and economic terms. Thus, provision of a well-organized home care has been adopted by many different countries as strategies to alleviate these problems by ensuring the continuum care (1).

Some studies indicated that in urban setting, bed occupancy due to AIDS has reached level as high as 50 % (3). This is an extremely big burden on the health care infrastructure that is already constrained. Certainly, the high demand for care cannot be met by health service alone, even in the most optimal health service system. The gap can only be filled by making care and support available at the community and home levels (1).

Therefore, HBC, it is the program that offers health care services to support the care process in the home of the HIV infected person (WHO/GPA, 1989), has been a major care and support strategy since the inception of the epidemic in different African countries. This was against a background of scarce health care facilities, difficulty in accessing the available care facilities by the very ill, and the preference for terminal care and death in the home setting (4).

Likewise, in Ethiopia, HBC programs are initiated and operated in a few area of the country by adopted it as strategy from other Africa countries. However, the practice has been diverse, not following any standards in terms of quality of care, even if the EMOH had developed a national guideline on 'CHBC for PLWHA' in 1996, to help organize the service (1).

To develop effective responses, research is needed to understand HIV at a terminal stage, the HBC programs, and their successful strategies. To date, no study that described the activities, impact, and the major challenges of VHBC was done in this country. This study attempted to gather and synthesis data from VHBC-givers in oromia region to identify range of HC activities that performed by VHC givers, and major challenges in HBC at Nazareth (Adama) town in order to informed further developments and research for building effective and sustainable HBC program in the study region as well as the country.

Literature review

The concept of HBC

The concept of caring for patient at home is not new in Africa (2, 5). There is a strong tradition of the extended family, being involved in all matters affecting the family, including the care for its sick and disabled members. HBC has to be viewed as one component in continuum of care and services necessary for optimal health care service delivery to individual with HIV or AIDS. Among home care services, those that provide a link or

mechanism of referral to a formal health care provider are more successful and sustainable than those that do not (2). In instance where such link do not exist, care provision often result in instance of neglect, since referrals for appropriate care cannot made (2).

HBC programs vary as to whether they concentrate on home visiting for the care of very sick AIDS patient (home care) or have a broader approach. The broader approach involves a 'continuum of care' of clinic based service and care for infections occurring earlier in the course of the disease, such as directly observed treatment (DOT), preventive counseling and condom promotion as well as home care for the very ill (community care) (5).

Community-based home care activities and its drawbacks

One of the models or initiative-programs for patient care in the community is NGOs or community based home care program. It is usually funded by international donor agencies and staffed by volunteers from community or/and by service professionals. The ranges of activities in this kind of program usually involve providing assistance with chores, spiritual and psychological support, food parcels, some nursing care, and palliative care. The major drawbacks to such programs are lack of smooth referral process for sick patients (especially true when programs are not linked with formal health care providers) and the potential non sustainability of resource (a factor for programs dependent up on donor funds which may be arbitrarily reduced or withdrawn) (2).

However, each program uses its own approach and sets its own goal. Some program-teams provide a nurse; some treat opportunistic infections; some provide drugs for prophylaxis and pain relief; some train volunteers; and some focus on improving the skill of the home caregivers (5).

Consistent with the comprehensive care strategy recommended for HIV/AIDS infected and affected individuals, HBC programs aim to alleviate human suffering and pain, and mitigate the impact of HIV/AIDS through comprehensive package of nursing care, treatment of opportunistic infections including symptom and pain; counseling and emotional support; assistance with essential like food and soap; poverty reduction.

The study in Uganda indicated that all the programs provided comprehensive care including nursing and medical care, psychosocial support including counseling, material assistance- school fee provision and income generating activities, orphan care, and spiritual care (4).

According to the FMOH in Ethiopia guideline for CHBC, the main component of HBC are medical and nursing care, spiritual care, education and training of care givers in the home, material and financial assistance to cover needs such as food, blankets, soap, income generating activities, and appropriate referral service. Family members, neighbors and other volunteers could provide the care. These care providers have to be given training and supervisory support from skilled personnel including health professionals, counselors, nutritionist, and social workers among others. The types of care that emphasized by the guideline are home nursing and general hygiene; supportive care, example, good nutrition; counseling; education of patient; preventions and early treatment of infections especially TB; prevention of malnutrition and pregnancy; and terminal care (1). Study in sub-Saharan Africa also indicated that trained CVHC givers participated in the daily care of the patient, especially by basic nursing care, counseling, and the provision of medical advice to patients.

Therefore, consideration of what constitutes HBC (quality end-of- life care) in non-industrialized countries is worthy of consideration; “total” psychosocial care in resource poor environments includes additional needs such as orphan care, income generation and food security. The care element of the programs constituted information, lay carer, family support, psychosocial support, comfort care, pain and symptom control, and palliative care (6). In general, the extent of the service depends on the HBC programs’ objectives, strategies, and available resources (4). An example of NGO initiated programs, TASO (the AIDS Support Organization) in Uganda, showed that the group’s initial goal of providing psychosocial support expanded rapidly to include VCT, preventive activities, and medical and nursing care for opportunistic infections were made available at seven centers through out Uganda, each center affiliated with government-run district hospital. In 1996 alone, TASO served a cumulative client base of 22,000 (5). Other study in sub-Saharan Africa indicated that the need for total care elements of emotional support, poverty mitigation, food security, traditional healing, orphan care and nutrition, water, shelter, sanitation through NGO collaboration were noted as areas for expansion. Additionally, in most of the programs, tasks of public education and prevention were identified. Community mobilization and establishment of links between hospices/palliative care and health system were seen as method of expansion (6).

Challenges in HBC

(a) Link to health services

Individual utilization of existing health services for HIV/AIDS may be affected by social barriers such as stigma, discrimination, and the equitable status of women in some societies. Factors such as high rate of illiteracy may also affect treatment-seeking behaviors. In addition, deep poverty often a result of HIV-related illness can affect the ability to pay for health care (7). The other factor is capacity and distribution of health care infrastructure, which affect the system ability to provide the wide range of health service required for HIV/AIDS care at population level. For example, access to and appropriate utilization of secondary and tertiary level of care, especially in urban and semi-urban areas, is affected by ineffective referral systems. Therefore, the infrastructure for optimal HBC is recommended to include referral systems linking the home with health facilities and social service, and transportation for HBC-givers based in clinic and hospitals (2). Study in Uganda also indicated that access to comprehensive care continuum by PLWHA was promoted through free treatment, waiver of co-payment for the very poor and appropriate referrals. In addition, most of the organizations offered transportation for home/community visit included: motor vehicles, motor cycles, bicycles, and foot when necessary. Most of the vehicles were donated by individuals and agencies (4).

In addition, constraints to the safe and effective treatment of opportunistic infections include poor availability of essential drugs and commodities, lack of skill among care providers at periphery level and inadequate laboratory access for diagnosis and monitoring, besides the limited health facilities to serve the population in need, are also affected the care process (6). A study indicated that an example of selected HBC programs which illustrate some of the constraints to achieving quality and coverage of services. At the Church of Scotland hospital in Kwazulu-Natal, South Africa, a HBC program relies on community health volunteers who reside close to patients' homes, to provide basic medical care and access to social support services. Volunteers receive referral support from the hospital. However, financial constraints make it difficult to access drugs for simple infections and palliative care. There are also difficulties in retention and sustainability due to the lack of incentives for volunteers (2). The same study in Uganda also indicated that the tenuous relationship between programs and

political leaders, and lack of formal linkage with health facilities were other sustainability problems (4).

(b) Challenges in medical care provision

One of the problems in HBC of PLWHA is lack of medical care knowledge and skill (6). Study in sub-Saharan Africa indicated that the vast majority of service providers reported their experienced challenges to providing pain relief. These were drug availability, lack of providers, transportation, stigma, and government restrictions. Additionally, other qualitative descriptions of challenges were: drug cost, lack of trained personnel to administer, lack of clinical expertise/awareness of pain control, patient inability to pay, fears of misuse of potent narcotic/under prescribing; appropriate pain relief drugs absent from essential drug lists; funder restriction on drug procurement; clinical disbelief in AIDS-related pain; patient not visit the hospital at late stages of disease; and lack of referrals. In addition, most of the programs addressed poverty effect on disease management and progression. Further description reported this as achieved through collaboration with multi-sector mitigation program, nutritional assistance and supplementation, income generation projects, safe house system/accommodation, assistance for food production, and crisis admission (6, 8).

(c) Inadequate support

While organized home care has many benefits, at present, in sub-Saharan Africa, coverage is very low due to inadequate financial resource and inadequate support for caregivers. As caseload escalate, out reach workers may find it difficult to meet client needs due to increased traveling time and costs, which may result in reduced frequency and duration of visits and poor coverage of service. For the family, caring for the patient at home may mean a heavy workload. For example, a study in Zimbabwe, it was found that care spent 2.5 to 3.5 hours a day on routine patient care. Due to adverse socioeconomic factors, patients may also be nursed in overcrowded and impoverished conditions. Furthermore, families and communities may be reluctant to provide care due to stigma and negative attitude (6).

Similar study in Uganda also indicated that the issue of inadequacy of health and safety measures at work featured prominently in the focus group discussions with the caregivers expressing concern about exposure to disease like TB without necessary protection (4,9). In addition, most of the studied home care services' concerns included insufficient working

materials like gloves, umbrella, gumboots, and bicycle for transportation; lack of material benefits such as salaries, and lack of protection from communicable diseases (4).

(d) Stakeholder participation:

HIV/AIDS is not primarily a medical but a socioeconomic and developmental problem that requires a multi-disciplinary response. Fighting HIV/AIDS has been compared to a national liberation war where every one is a stakeholder. Although community leader and organizations are expected to play a coordinating role in program development and implementation, the health service and other outside organizations must provide technical and material support (10).

Therefore, partnerships between Kebele, NGOs, the private sector, and government agencies can provide much-needed technical assistance, information, and knowledge through partner networks and thus better services, participation, best practice, and monitoring and evaluation of patient care and support program (5**). Study in Uganda indicted that the religious and civil leaders were actively involved in the promotion of HIV/AIDS awareness, facilitating programs' activities, and in one instance contributed land and water to the program for building of a farm school for AIDS orphans. The political leaders, though acclaiming the work done by the programs, had no working relationship with them, and felt that home based care was an area for the health officials only. However, in the coverage area by one of the programs, the grass-root political leader's desired involvement and participation in the program activities, as they felt that only the elite leaders were currently involved (4). Another study in sub-Saharan Africa also indicated that traditional healers playing a role in local health belief and practice. The influence of traditional healers manifested in an estimated 80% of patients seeking their advice, leading to delayed clinical presentation and medical intervention. Traditional healers were often included in care and education programs, with religious leaders along with spiritual care service, and were seen as key to gaining community approval and improving service uptake (6).

Similarly, it was suggested that the government has provided the enabling environment for HBC programs in the country, though with minimal support in terms of collaboration, monitoring and logistical support. There is inertia on the part of the government to coordinate

the HBC activities in the country (11). Other study in Uganda also indicated that all the studied programs were beneficiaries of the government and donor agencies' technical/capacity building programs (12).

(e) Community support

Among the areas of the CHBC programs in the new guidelines are: family and community mobilization, establishing an effective two-ways referral system at all levels that can contribute to the provision of quality patient care, and training and orientation of various groups that would eventually be included in the CHBC implementation process (1).

Therefore, Community mobilizations, in order to motivate the strong extended family tie and community commitment, are major components in viable HBC programs that not only include PLWHA but also orphans and vulnerable children. Especially neighbors' women, volunteers from faith-based organization and private organizations, group of PLWHA, the Kebele and NGOs support through food and materials have been major actors in HBC in Ethiopia (8,10). A study revealed that some iddirs in four regions in central and southern Ethiopia help their members with transport cost for visit to clinics and to teach about AIDS. In addition, iddirs-leaders together with teachers and religious-leaders were highly supportive and willing to supervise TB patient care in the home, indicating their possible utilization in HBC of AIDS patient as well (8).

Moreover, it is also indicated that the key to successful HBC at the community and wereda level may be the development of community initiated care that freely develops in an enabling environment free of fear and stigma and where PLWHA and local organizations can play both care/support and advocacy roles. This can promote a sense of community ownership of the initiatives to be developed and thus increases the likelihood that they will be designed according to local needs (8, 11).

But, even if plan to promote community participation in health care delivery and IEC programs can benefit community based-HIV/AIDS programs, more information is needed about what community and culture groups perceive as appropriate care in order to maximize the benefits of care for AIDS patient (13, 14). As experience from another PLWHA-founded group show that patients prefer to be cared by people sharing the same problem (8). Study in

Zambia also indicated that many family members provide nursing and medical care with the support of trained community volunteers. Welfare support such as food cloth, money also provided. Trained volunteers and religious leaders provide counseling, emotional, and spiritual support, while friends, family members, or volunteers provide practical help for certain household duties (11).

(f) Health staffs support

Similar study in Zambia also indicated that community nurse carry out home visit accompanied by community volunteers and provide medical, nursing, and psychosocial care. The community nurse and community volunteers performed a wide range of tasks. Moreover, the nurse-counselor supports the family carers and volunteers in their activities and provides medical and psychosocial care through home visits (11). The community volunteers also worked under the supervision of nurses and under volunteer visiting doctors in HBC programs in this study (4). However study in Nigeria also indicate that some health staff had discriminatory attitude and practice to wards PLWHA in health facilities (15).

(g) Education and information

Community education programs for HIV awareness and prevention, behavior change and stigma reduction, were organized for churches, schools, and the public through talks, drama, songs, and community radio (6).

The same study in Uganda indicated that all the programs had appropriate home-based care education-programs for the team and family caregivers and community volunteers. Training included counseling to obviate the need for or reduce the number of full counselors needed. Moreover, the study indicated that the community volunteers in the FGD acknowledge the quality and the content of their training and their impact on the HIV/AIDS situations in their community. Specifically they had been active in the area of community education /awareness program for behavior change, stigma reduction, and condom distribution (4).

A study in sub-Saharan Africa also indicated that the need for clinical training for home care givers was recognized as necessary in providing a “good death,” including training in pain and symptom control and the treatment of opportunistic infections (6).

3- OBJECTIVE

3-1. General objective:

The objective of this study was to explore contextual based HBC activities, by describing the range of home care activities performed by volunteer home caregivers and the major challenges in home based care.

3-2. Specific objectives:

- To describe the range of home care -activities performed by volunteer home caregivers.
- To identify major challenges in home based care.

4- METHODOLOGY

4-1. STUDY AREA AND PERIOD

The study was conducted in Oromia region, Nazareth (Adama) town from October to May 2006. It is located in the rift valley, 100 Km east of Addis Ababa.

Administratively the town is divided in to 20 Kebele. The total population number in the town estimated to be 218,110 (Male = 106,874, Female =111,236, i.e. M: F (0.9:1)). According to the FMOH, Health indicator in 2005, the number of PLWHA in Oromia region is estimated to be 1,590,967. According to the data from Adama health centers, the prevalence of HIV/AIDS in the city was estimated to be 9.0 % (16).

Because of geopolitical and business activities, Nazareth invites different types of people looking for job opportunities in state farms and factories. Besides, in Nazareth, most people are dependent on a petty trade with a daily subsistence income, some selling a local prepared beverage such as Tella, tej, and Arki. There are also several bars, hotels and red light houses that attract visitors there by accelerating the spread of HIV/AIDS.

On the other hand, there are 22 NGOs who have been working on HIV/AIDS prevention and control activities in the town. In addition, there are 29 Anti-AIDS clubs, 8 VCT centers, and 2 Health facilities that provide PMTCT service in the town.

However, out of the 22 NGOs, only six organizations were found working on care and support services specifically HBC for PLWHA.

According the document reviewed, the number of CVHBC givers in the town also to be 180 to 200.

4-2. Study Design

This qualitative research utilized a cross-sectional study design. This method was chosen according to the objective of the study in order to explore contextual based HBC activities.

4-3. Population

4-2-1. **Source population:** the home care and support teams that provide HBC for

PLWHA in Nazareth town.

4-2-2. **Study subject:** A sample of CVHBC-givers for PLWHA in Nazareth town who were members of HBC-Teams in the care and support organizations.

4-7. Sample size and sampling procedures

In keeping with qualitative research methodology, the purpose of determining sample size was to reach redundancy or saturation of the data. List of names of VHC-givers was obtained from the six home-care and support organizations. Then those who had the highest work experience and service duration were recruited for the study according to the inclusion criteria using a purposive sampling . Then we arranged days of interview with the help of team leaders.

4-8- DATA COLLECTION

This qualitative research methodology used semi-structured open-ended interview guide for in-depth interview and FGDs, which were adopted from standardized interview guide questions (17).

These questions were slightly modified so as to relevant for the study objectives and according to the local context. It was initially prepared in English language and then translated in to Amharic language for data collection process.

Then, data collectors (2-interviewers and 2-raportres for in depth interviews, 1-facilifator for FGDs, and 1 supervisor) who have first degree and diploma were recruited. All had at least one experience in conducting qualitative interview.

For the purpose of this study, a four days training were given for all data collectors and their supervisor. The training was focused on reaching to consensus by discussions about the meaning and relevancy of each questions and the technique of interviewing an open-ended question by using a qualitative data collection guide manual.

And then, pre-testing of the open-ended interview guide for its clarity, understandability, completeness and reliability were conducted prior to actual data collection on similar study subject who were not be included in the study. Then modification on a few questions and retraining for data collector and supervisor were under taken for one extra day. During FGD, tape recording was used.

4-9. DATA QUALITY CONTROL

-To reduce interviewer bias, trained and experienced data collectors and supervisor were used.

In addition, repeated demonstration and role-play were done during the training.

-We used a private room for each interview.

-Confidentiality of participants was assured before the interview.

-Written consent for organizations and informed consent for participants were given.

-Each steps of in-depth interview were controlled by supervisor.

-Each response was checked for completeness and consistency by the supervisor and researchers before coded.

-Data triangulation was done to cross-check qualitative information. In addition, multi-disciplinary team were used to collect information and during data transcription.

4-10. DATA ANALYSIS PROCEDURES

The data were analyzed based on pre-identified themes assisted by computer software for qualitative data processing.

The data analysis procedure was started with the process of data collection on a daily basis. At the beginning, the collected response/ data were translated back to English. Then after, each data were entered to the open code soft ware program version 2.1 June,2001, in order to give code for each response.

The first step was coding the data. That is, code for responses were assigned by selecting words from the response or/and by developed concepts from the response which are characterized the important information of the response. After completed the coding process for all data, friends were invited to add extra codes or commented the codes. During this time a memo was used which contained different ideas, concepts and narratives from data.

The second step was re-grouping the codes into pre-identified themes of the study.

Then each code under the pre-identified themes were described and explained according to the respondents' contextual meaning that related to the study objectives.

Finally, the study findings were reported with supplements of verbatim citations of the participants' view presented in their own words.

5- Ethical consideration

The study was approved by the ethical committee of A.A.U , Medical faculty. Informed consent was obtained for each study participant.

During research process, the investigator spent a long period in the field to build trust with the study participants and provided detail description on the context of the research.

In addition, peer- debriefing was made to receive input and comment.

6- OPERATIONAL DEFINITION

Home based care: The WHO definition of HBC is a program that, through regular visits offers health care services to support the care process in the home environment of the person with HIV-infection

Home care: care that provided in the home environment of PLWHA.

Community home based care: is community or/and NGO-based initiative HBC for PLWHA that supported by donor agencies and staffed with volunteers and some times health professionals

Person living with HIV/AIDS: Individual who is sero-positive for HIV –test and manifested clinical symptoms.

Volunteer home caregivers: people who provide home care service for PLWHA by their own willingness.

Result

A total of 30 individuals' in-depth interviews were conducted with a purposive sample of community volunteer home caregivers in this study. In additions, at the end of in-depth interview, two focus group discussions were under taken with a total of '16' participants that consisted of volunteer home caregivers and their team-leaders (all team leaders from each HBC-team were participated.)

These FGDs participants were recruited according to their experiences related to the study topic, their willingness, work position, and activities in HBC-program besides their similarity in relevant socio-demographic characteristics. This was carried out by using the HBC-coordinators as contact person and by documented review.

The findings of this study were described in three major categories: VHC givers' perceptions to HBC of PLWHA, The range of HC activities, and the major challenging issues in HBC.

HBC perception: The respondents in this study perceived that HBC is helping the PLWHA by providing necessary care and support according to their needs in their home. Continuum of care from hospital to home and from home to hospital with out gap was emphasized. They believed that one of their major roles was doing as mediator between patient and health professionals in order to narrow the gaps between home care and health facilities besides helping the family caregivers by providing home care training and home care of PLWHA. According to their perceptions, the HC that provided to the patients should include medical care, physical care, nutritional care, psychological care, spiritual care, emotional care, supportive care, and finally dead body care. Similarly, the supports should also be adequate, on time, and continuous until the patients started to provide self-care and to support by themselves.

Moreover, a good approach to patients was indicated as important strategy in order to have a positive relationship with patients. Since, they believed that home caregivers should be empathic and see their patients as relatives or good friends when they provide the care. It meant that while they approached friendly and visited them regularly, the patients become happy and expressed their feeling with out fear and hopefully. As one VHC giver shared his experience:

Most of the patients at the beginning, observe our face and they evaluate our approach, and then they become open or not, to share their problem or feeling. Since they preferred people sharing their problems, or those who shared the same problem to give them the home-care.'

However, the majority of the respondents believed that all people including those who are HIV negatives should be encouraged to participate in HC provision.

They strongly suggested that all community members, social organizations, Kebele leaders, all religious organizations, government organization, health professionals, and all NGOs needs to be participating in order to implement the HBC program efficiently and effectively.

One VHC givers expressed his felt:

“In the existing situations in our country, it is difficult to provide care and to help those patients only by VHC givers. There is a need of community, government, and NGOs participations.”

Even though some of the respondents in this study mentioned that the Home care work was heavy and difficult that brought health problems like physical injury and respiratory disease to them, they explained their interest to continue as volunteer. Since they believed that they would get spiritual benefit, and any types of incentives from Kebele.

Range of HC activities: The majority (almost all) of the respondent VHC givers described that they gave a limited range of care for their patients. The common/routine types of care that provided to their patients were body bath, hair care, nail care, washing clothes, cleaning the house environment, preparing food and feeding the patient, giving advice, provide health information, provide medication to the patient on time like TB drugs and ART, turning patient on bed, refer patient to hospital for medical care and some times they gave care of dead body.

In addition, even if few of respondents reported that they provide medical care such as paracetamol for pain and headache, local medications for skin and eye problems, most of VHC givers did not agree on the provision of medications without observation and examination by health professionals. Therefore, they preferred to refer the patient to hospital for medical care. Since, all of them believed that they have lack of adequate medical care knowledge and skill. On the other way, some of them reported that they were provide wound care and home remedies like rice water for diarrhea and applied ‘papaya-water’ on skin wound.

Nevertheless, most of the respondents mentioned that they performed these activities according to the patient’s health conditions, the available materials in the patient’s home,

adequacy of medical supplies in their kit and the available time that they have. Some times because of lack of equipments and shortage of time due to transport problem and patient load, they performed a limited range of care. As one VHC giver noted:

Some times, I only visit some of my patients and return home without giving care. Because of lack of equipment and absence of materials in patients' house, it is difficult for me to help these patients, even to prepare food. However, I have tried to help and feed them by collecting food from near by hotels and restaurants.

Even though some of the respondents expressed their desire to provide the whole component of HC to PLWHA, they believed that they were providing inadequate and sub-standard care. In general, they explained that because of the lack of materials in patient's home including shortage of water and food, shortage of medical equipment, financial problem of patient, severity of the patient's illness, lack of adequate knowledge and skill, and time shortage, they were providing a limited range of care. Because of this, they expressed their felt of becoming dissatisfied, emotionally stressed, and confused.

However, some of the respondents reported that, even if they tried to give care by using the available materials, the patients as well as their families some times rejected their care and abused them.

Therefore, the need of re-organizing and adjustment of the existing HC program by preparing adequate and sustainable resources such as work force, materials, and financial resource and improving the system were reported by most of respondent VHC givers.

Challenges related to the provision of HBC for PLWHA.

The data in this study also revealed general issues that affected the respondents VHC givers in the process of HBC provisions. These general concerns were included: the overwhelming problems of poverty; stigma, rejection, and abuse; lack of education, information, supervision, and support; and lack of an adequate infrastructure for HBC.

Poverty: One of the most pervasive themes through out this research was the experience of poverty. The majority of respondent VHC givers explained that most of their patients received this HC and support services were those who are living in poor condition. They are experiencing profound problems of basic materials in the house, which are very essential for

their daily life activities. As a result, the HBC activity has been severely compromised. There were reports of VHC givers' confusion and dissatisfaction in the HC giving process due to shortage as well as absence of house material and financial problem of the PLWHA that made them not to do what they planned to do for the patients.

Absence and shortage of Water was reported as a problem in the study area. The respondents explained that, in some areas many families were required to purchase water from a central location. The cost and inaccessibility of water resulted in use for human consumption and not for washing and other sanitary purposes so the family as well as neighbors not allowed sharing the water for cleaning the patient. Therefore, this made the care giving process to be limited.

In addition, care for a sick family member at home was also mentioned as one factor that created poverty. Since, cost of care, drugs, medical supplies, and transportation had to be born by the family. Consequently, families used what little financial resources they had on caring for their ill family member. The sick person was also often the family income earner. Therefore, families become increasingly poor as they tried to provide adequate care to the sick family members at home. Due to this, they became hopeless, uncooperative, and disinterested to participate in care of patients. One VHC giver reported on this:

Most of our patients are poor, helpless, and weak. So we can't do what we should do.

Therefore, first of all these patients should be supported with adequate food and house materials. Other wise, it is difficult to give care. Really, it is very difficult.

The other thing, I have also patients who have families. However, the family sold all their material to give care for the patient. Finally, they became hopeless and poor. They don't support and participate on patient care. They ignore the patient as well as my work.

Stigma, rejection, and abuse

Through out this report, stigma was also reported to lead to discrimination, isolation, rejection, and abuse. Most of VHC givers reported that many of their patients were stigmatized by their family and community members. Because of this, patients as well as families have no interest to be visited by HC givers in their home. Therefore, it was mentioned that stigma was one major factor for inaccessibility of HBC.

More over, health care professionals at hospital were also reported to stigmatize PLWHA and

their families. Issues of confidentiality were reported to be breached with disrespectful behavior toward PLWHA and their families. As one VHC giver noted that when he take PLWHA to hospital as referral:

There are many staff in the hospital still demoralized patients because they are announcing loudly that the patient has AIDS and hopeless. They also told us no need of admission for this patient. They give priority for others. The patients hope is lost when they hear this. Actually, confidentiality is lost.

So that, they reported that patients were feeling vulnerable to the abuse of others and were unaware of any support mechanisms available to them. These patients as well as their families have no interest to visit health facilities in their areas. There for, it is one of major institutional barriers that affected the home care process, which needs urgent solution.

Lack of education, supervisions, and support

There was a profound need for education by respondent VHC givers through out the HC system. They all expressed a need to know more about counseling service and medical care for common opportunistic infections of PLWHA. Some of them received little or no education on basic nursing care, universal precautions, administration of drugs, use of medical supplies and other form of patient care. As a result, patients were receiving substandard care. The lack of knowledge and skill on patient care with the absence of protective devices for caregivers mentioned as the cause for developing health problems like physical injury and some respiratory diseases. One VHC giver reported on this problem:

I do not know how to care for my patient. No one came to show me what to do. She has drugs and wound on her body, but I do not know how she take the drugs and to care her sores. I use a plastic cover for my hand “feistal” to clean her body, there is no one show me what to do and how to do. However, still I am trying to help my patients.

In addition, those VHC givers also reported a need for further training. They voiced dismay at their inability to provide the kind of service that they think they should. They also emphasized the need for education on health care matters and how best to counsel patients and families. Since they didn't know how to provide emotional support and counseling to individuals and families. So that, they expressed that the family members not only lacked education on the

necessary knowledge and skills required to care for the patient at home, they also deprived of much needed psychosocial support and counseling. As one FGD of VHC givers stated:

We lack appropriate knowledge and skills. We need continued training so that we can give training for family caregivers. There is very little education on patient care. We need counseling skill to reduce the tension and to assist the people to live positively. Because we are, the one that know a whole secrete of the patient. We need also to help with community awareness so that people are able to ask questions and to understand and deal with their situations. We need also seminar to become enlightened.

The other issues, those VHC givers reported with felt that the health professionals from government as well as NGO were not participate in HC service. They did not give support and supervise the HC activities. Because of this, they reported that they were in problems to teach or advice what little they could about patient care, especially issue related to medical care. Therefore, they expressed their need of professional support.

Additionally, they mentioned that there is a need of community participation even though there is still community stigma and discrimination in some areas. One of the reasons that they mentioned for this community stigma was the absence of community mobilizations and continuous education for the community. Because of this, they believed that now days there was the general ignorance about the full magnitude of HIV/AIDS. This general ignorance contributed to these sigma and discriminations. One FGD of VHC givers commented:

There is no community participation in HC of PLWHA. They have still a negative attitude to wards HIV. They saw us “as HIV/AIDS-Patient.” Therefore, Kebele leaders should participate in mobilizing the community. There should be a continuous health education for this community. In addition, the government has not giving emphasis for HBC. It seems he has no any concern for these patients.

Concerning NGOs’ support, they reported that, in the past some of them used to visit the home, but as the problems of caring for PLWHA grew, these services become overwhelmed. However, still they have provided material and financial support for some of the patients living with HIV/AIDS, even if there is lack of adequate and timely support.

In general, VHC givers expressed that there was a need for continued support from all community members, government, as well as NGOs. One VHC givers explained that “caring for PLWHA and the care givers was emotionally draining and would lead to burn out. In

order to continue this important work, there should be psychosocial support for the patients as well as HC givers from all stakeholders in the community.”

Lack of adequate health care infrastructure

An adequate infrastructure to support the care of PLWHA at home noted to be a pressing issue in this study. Specifically the following infrastructure requirement were reported to be necessary: (a) an adequate functioning referral system; (b) the provision of adequate supplies at the periphery of care; (c) the development of a transparent egalitarian wavier system; (d) better communication among HC organizations, NGOs, church organizations, private health care and the public health care system; and (e) The provision of affordable (or free) transportation.

(a) Adequately functioning referral system

Data from the interviewed VHC givers and from FGDs provided that there were no formal way of referral system in HC process in their area. Although referrals of patients from hospital, health centers, and from community to HC teams were reported, they mentioned that there was a serious gap in this referral process. These gaps appeared to be most acute between the health facilities and the home. One HC team leader explained this gap: “many patients come to our organization as referral. However, no one assist them to reach to us. Most of the time, they reached to us through passing many challenges and after two or many days. They only held a single paper from hospital and Kebele or they came to us with out referral paper and lied down on the floor.”

In general, most of the respondent VHC givers in this study noted that there was no formal policy in placed to support referral from the periphery to the central health care agencies in addition to their judgments regarding patient referral was seldom respected by health personnel at the hospital. Therefore, referral from the home and community to the necessary health care facility was reported to be severely compromised the HC activities.

(b) Supplies at the periphery of care

The vast majority (almost all) respondent VHC givers reported that one of the major issues was lack of essential equipment in HC process. They mentioned that shortage of medical

supplies such as glove, cleaning materials, medications, and protective device were some of the factors that affected the HC giving process. Likewise, lack of essential medicine and other medical supplies at the health facilities were reported as a factor that severely compromised the services. Because of this, many patients and families lead to the inappropriate and costly use of private pharmacy. Moreover, these shortages of medications and other health care supplies to VHC givers to take to patients' home, make the VHC givers to give inadequate or sub-standard care. Therefore, these respondents noted that a constant supply of HBC kits would be required in order for HBC to be successfully implemented.

(c) Transparent, egalitarian waiver system

Many of the respondents and patients were unaware of how to successfully access to the waiver system in health facilities. An example was given of a VHC giver who brought a patient to hospital for medical care. However, the VHC giver could not access to a social worker, no one was informed or assisted him, and so the fee waiver was not given. As a result, the VHC giver and the patient went home with out any medical service. So that, most of the respondents mentioned that because of the sever poverty, it was necessary that a waiver system be implemented i.e. easily accessible, open to all who need it, and transparent in its delivery. They also suggested that the government must explore option to ensure sustainable financing for health care (including HBC) where payment at the point of delivery is not required by the family or patients.

(d) Communication among home care organizations, NGOs, and the private and public health care system

There was a general belief and agreement among the study participants that community based VHC teams, PLWH-groups, few NGOs based HC teams, and very few religious HC organizations were doing most of the work in care for PLWHA in their home and in the community. They stressed these organizations as a valued resource within the overall health care system that should be maintained and supported.

However, they expressed that there was a lack of communication among these complementary organizations and with the government health care system. This meant that patient care was

sporadic and uncoordinated with gaps in reporting the patients' conditions and prescribed treatments of care from health facilities. As a result, patient care across the continuum was severely compromised. The respondents stressed the need for better communication between the complementary health care agencies, social service agencies, and the government system.

As one VHC givers noted:

We need to establish a continuum of care from hospital to home and home to hospital with no gaps in care. So that, there should be formal communication and work relation ship between us. This care needs to be systematic and comprehensive. The gaps happen mostly between the health facilities and the home. There are major gaps. For example our communication with health care workers at hospital is not good since there is no prompt attendance when you bring the patient to hospital. Some times, we are abused and cursed by the health workers at the facility. However, not all, some times the social worker assist when we run in to problems.

Other VHC givers also added:

I find people at homes with medicine but I don't know what they are for, often neither does the family. I am left being unsure what I should be doing to help the patient since I have no one to consult. The health workers also didn't visit and supervise our work.

(e) Affordable (or free) transportation.

One of the major problems mentioned by respondent VHC givers in the process of HC provision was the absence of affordable or free transport service. Even though a few HC organizations have motor bikes and vehicle for referral of patients to hospital, and bicycle for home visit, these VHC givers complained that it is not adequately functioning because of fuel shortage and maintenance problem. Others VHC givers also reported that they get financial support from their organization for transportation during home visit. However, they mentioned that the money is not given on time as well as it is not adequate. Because of this, they forced to travel a long distance on foot to visit each patient. So they become physically weak and lost much time without giving adequate care.

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 unable to pay for transportation, then visit to the relevant health care agency would not occur. As one VHC givers commented:

I know a severely ill patient who died due to lack of medical care in hospital. This was due to

absence of transport and lack of community help to take him to the hospital. Therefore, the respondent VHC givers suggested that there should be affordable or free transport service for each HC organization in order to implement efficient and effective HC for PLWHA.

Discussion

This study was exploratory in nature and it has provided some important insights in to the experience of VHC givers and the challenges in providing HBC to PLWHA at home. In addition, the study has shed light on the general infrastructure that is required to incorporate an effective and responsive HBC program.

The major findings indicated in this study are the VHC givers in Adama (Nazareth) town perceived that HBC is a continuum of care that help PLWHA by providing basic care according to their needs in their home without any gap between health facilities and HBC. Moreover, they believed that they acted as mediator between health facilities and the patients. However, the HBC process in the study areas were indicated that it was unorganized and not coordinated which means, there was lack of professional support as well as adequate materials and financial support besides the lack of all stakeholders' participations and the absence of communications among the organizations. Due to this, the HBC activities that performed by VHC givers were limited in range and the types of care that provided for PLWHA were inadequate care. In addition, the overwhelming poverty; stigma and abuse; lack of training, professional's supervision, and support; and lack of adequate health care infrastructures were identified as major challenges in HBC.

According to the guideline on CHBC for AIDS patients, the range of HBC activities that can be performed by HBC providers are from medical to psychosocial and material support (1). However, the VHC givers were providing only few of care from the components of HBC that need to be given for PLWHA by HBC providers. The types of care that were reported as a common/routine care usually provided by most of VHC givers were physical and environmental care, such as body bath, hair care, nail care, washing cloth, clean the house,

nutritional service, providing advice, follow the patients to take the ordered medications, and referral of patients to hospital.

However, the other components of HBC such as medical care, provision of information and education, counseling, networking, and other supportive services were mentioned that did not adequately perform by the majority of VHC givers.

Moreover, it was indicated that these care and in occasion other components of care were performed according to the patients' health conditions, the available materials in the patients' home, the adequacy of medical equipments, and the available time that they have.

Concerning medical care service, a few of them were mentioned that they provided paracetamol for pain and headache, applied local medications, giving wound care and used home remedies to treat medical problems of the patient. However, the findings in this study indicated the presence of role ambiguity about medical care provision by respondent VHC givers. Most of them believed that health professionals should give medical care service. So that, they preferred to refer the patients to hospital for medical care service. The reason that was mentioned by respondents was lack of medical care knowledge and skill, and insufficient working materials (4).

Therefore, this study indicated that patients were getting inadequate or sub-standards care. Because of this and the inability to meet the priority need of patients, most of the respondent VHC givers reported that some patients as well as their families were become disinterested, uncooperative and sometimes they rejected the care and abused them.

The reasons that mentioned for the provision of limited range of home care for PLWHA in this study were lack of adequate medical equipment in HBC kit, absence of adequate materials in the patients home that included absence or shortage of water, food, financial problems of patients, severity of patients' illness, lack of adequate knowledge and skill, and time shortage (2, 5). Even though these reasons were indicated for the limited range of HC activities in this study, the other issue that needs to be considered is the nature of the designed programs. Literatures are explained that the types and range of HC activities may differ according to the goals and objective of each model of HC initiative-programs (whether community-based or Hospital based initiated-HC programs).

.The ranges of activities in community based initiated HBC program are usually involves providing assistance with chores, spiritual and psychological support, food parcels, some nursing care, and palliative care. The major drawbacks to such programs are lack of smooth referral process for sick patients (especially true when programs are not linked with formal health care providers) and the potential non-sustainability of resource (a factor for programs dependent up on donor funds, which may be arbitrarily reduced or withdrawn). However, each program uses its own approach and sets its own goal. Some program teams provide a nurse; some treat opportunistic infections; some provide drugs for prophylaxis and pain relief; some train volunteers; and some focus on improving the skill of the home caregivers (5).

Therefore, in order to implement optimal HBC in the areas, there should be contextual based designed programs that involved the HC providers as well as the community besides identifying the perceptions and the priority need of the beneficiary related to the program (5, 8, 14).

The other issue identified in this study is the major challenges in the provision of HBC for PLWHA. Which are the over whelming poverty; stigma and abuse; lack of education, supervision, and support; and lack of adequate health care infrastructure.

The socio-economic problems that included the absence/ shortage of basic materials in patients' home and shortage of water in the areas were indicated as some of the factors that affected the HBC provision. Although there is no studies that indicated degree of poverty at household or community level in the study areas, in the context of this study the findings indicated that most of the patients were living in a very simple dwelling, which has no furniture, unventilated, earth floor, no light, and no convenience. Moreover, patients are weak, helpless, and they have lack of food, clothes, and financial problems. In addition, the patients' families become increasingly poor as they tried to provide adequate care to the sick family members at home were indicated (7). As a result, the families becoming hopeless, uncooperative, and disinterested to participate in care of patients were mentioned (5).

HIV/AIDS is costly to most household and communities. During periods of illness, medical cost rise, work and incomes are disrupted, the loss of family head undermines a families'

income generating abilities, adding to the work of burden of surviving family members, including children. Therefore, AIDS-affected families may experience rapid transition from relative wealth to relative poverty. For poorer households, the ability to cope with external shocks, such as inability to buy basic house materials or increases in the price of staple products, will be reduced further (7, 13). There for, the economic impact and consequences of HIV/AIDS on household and community is a major issue that needs to be considered in programs designing and implementation (7).

What stands out from this study is how HIV/AIDS induces impoverishment of many (but not all) affected households. Income is lost and assets are sold in order to get cash. Widespread disinvestment of assets appears to be occurring as households spend their savings and wealth to cope with HIV/AIDS (7). So that, it was suggested, that the need of poverty reduction strategies in order to implement HBC programs effectively and efficiently (7, 8).

In poverty reduction program, even if institutional support seems a critical factor in assisting households, some communities do provide support for affected households without external interventions (5, 8, 15). However, the need of government involvement besides community mitigation effort and initiatives such as social organizations like iders', rich persons', and volunteer NGOs' support in the community were suggested as means to establish such programs (such as income generating activities as well as establishing water source, and provide some house materials).(5,7,8).

Similarly, stigma to patients and their family by health staff in hospital and by community members were mentioned as factors that affected the HBC service for PLWHA (6, 15). Verbal abuse and discrimination during admission of patients with AIDS in hospital by few health staff were reported in this study. Similar study in Nigeria also indicated that health professionals reported that refusing to care for a patient with HIV/AIDS, and they had refused a patient with HIV/AIDS admission in hospital. While a few professionals reported verbally mistreating a patient with HIV/AIDS. Some other also reported that health professionals giving confidential information to a person not related to a patient without consent. The same study also showed that health professionals' agreement with the statement that treatment of

opportunistic infections in patient with HIV/AIDS wastes resources and treating some one with HIV/AIDS is a waste of precious resources (2, 15).

Therefore, which is an important area that needs special emphasis to reduce and avoid these social as well as institutional barriers (that are community and health staff's stigma). Similarly, it was suggested that to prevent stigma and discrimination by health-care professionals against patients with HIV/AIDS, health-care professionals who engaged in discriminatory practice should be educated and counseled by established a system to identify them through a report from clients by prepared suggestion box and others. In additions, health facility policies against discrimination as solutions, and need of stronger laws against discrimination were suggested (15).

Health staff involvement in HBC team is believed to be a means to narrow the gap between health facilities and the HBC service (11). However, the over all absence of health professionals' participation in HBC of PLWHA in the study areas in addition to the home caregivers' lack of medical and counseling knowledge was indicated as one of the factors that affected the HC provision process.

Likewise, the presence of some community stigma, and lack of adequate community support and participation except a few social organizations such as iddirs and hotels that supported patients by provide blankets and food, were mentioned in this study. The reasoned that explained by these VHC givers were the absence of Kebele-leaders' participation by mobilizing and motivating the community to involve in HBC process.

Therefore, the need of community mobilization and motivation were suggested as a means to reduce stigma and discriminations besides awareness' rising programs in order to make the community to participate in the HBC program (7). Similarly, it was suggested by other study that the key to successful HBC at the community level may be the development of community initiated care that freely develops in an enabling environment free of fear and stigma and were PLWHA and local organizations can play both care/support and advocacy roles. This can promote a sense of community ownership of the initiatives to be developed and thus increases the likelihood that they will be designed according to local needs (1, 6, 8).

In general, needs of all stakeholders' participation in the community were suggested in order

to implement optimal HBC-program for PLWHA. This was also supported by other study that HIV/AIDS is not primarily a medical but a socioeconomic and developmental problem that requires a multi-disciplinary response. Fighting HIV/AIDS has been compared to a national liberation war where every one is a stakeholder (8), although community leader and organizations are expected to play a coordinating role in program development and implementation, the health service and other outside organizations must provide technical and material support (8,10).

Lack of adequate health care infrastructure was also indicated as a major problem in the HBC provision process. This study indicated that because of the absence of formal referral policy, there was a serious gap between the HBC service and health facilities in referral process (2, 5, 17). In addition, health personnel at hospital seldom respected their judgment regarding patient referral. Therefore, referral from home and community to the necessary health facilities was reported to be severely compromised (5, 12, 17).

Moreover, the absence of essential medicine and other medical supplies at the health facilities severely compromised the HC provision process (4, 7, 13). Because of this, patients and families were forced to purchase from private pharmacy. It was also indicated by other study that constraints to the safe and effective treatment of opportunistic infections, include poor availability of essential drugs and commodities, lack of skill among care providers at periphery level and inadequate laboratory access for diagnosis and monitoring besides the limited health facilities to serve the population in need, are also affected the care process (2, 5). Therefore, constant supplies of medical equipments at the periphery level of the service were noted that would be required in order for the HBC to be successfully implemented (2, 6, 17).

In addition, because of sever poverty, it was indicated that a waiver system is necessary to be implemented in health facilities, i.e. easily accessible, open to all who need it, and transparent in its delivery (17). So that, the government must explore option to ensure sustainable financing for health care (including HBC) where payment at the point of delivery is not required by the family or patients (2, 4).

The other issue indicated in this study is the absence of communication and work relationships

among all HBC organizations, NGOs, and the private and public health care systems. Especially, lack of communication between these complementary organizations and the government health care system may cause patient care to be sporadic and uncoordinated with gaps in reporting the patients' conditions and prescribed treatments of care from health facilities. As a result, patient care across the continuum compromised. So that, it was stressed by respondents that needed for better communication between the complementary health care agencies, social service agencies, and the government health care system(4).

In addition, because of lack of adequate health care infrastructure for HBC including the absence of affordable or free transportation for referral of patient as well as home visit for home caregivers severely compromised the home care process (4, 5). It was also indicated by other study that as caseload escalate and due to lack of transportation, out reach workers may find it difficult to meet client needs due to increase traveling time and costs, which may result in reduced frequency and duration of visits and poor coverage of service (5, 8).

Strength and Limitation of the study

Despite this comprehensive review, certain study limitations exist.

As a qualitative research study, the decision on how many people to interview rested on reaching data saturation or redundancy. Members of the research team believed that data saturation was achieved. The team began to hear the same issues repeated by research respondents some times on many occasions. Therefore, it appeared that 30 interviews with individual VHC givers provided enough data to be confident that these results adequately represented the experiences and perceptions of the research respondents.

However, in keeping with the tenets of qualitative research, no claims to generalizability of these findings can be made. Generalizability is considered in light of the “fittingness” or “applicability” of the research results to other populations of VHC givers engaged in home caring for PLWHA at home. That is, reliability and validity of the research depends, to a large extent, on testing the ‘fittingness’ or ‘applicability’ of the findings to other study populations. The study was conducted in one of the urban city of Oromia region, Adama town.

Despite the respondent VHC givers from six different home based care and support organizations, the data from respondents of all studied HBC teams identified very similar issues. Therefore, it would appear that although claims to generalizability cannot be made, it is very likely that the findings of this study reflect the experiences of VHC givers throughout all home care and support organizations in Adama town. It is also important to note that some of the study findings had already been documented by others studies in Africa countries. That is, the findings from this research similar with findings from previous other HBC studies conducted in Zambia, Uganda and Kenya, and many of the issues identified in this report were also identified in these studies. Therefore, it can be assumed that the finding of this study and the previous studies provide some silent prospective on the experience of providing HBC to PLWHA at home, regardless of the study location.

While this study focused on CVHC givers, it is important that include PLWHA and families' care satisfaction and data from health professionals, which were not included in this study. Therefore, it is recommended to be addressed by other study.

Furthermore, Absence of previous study (data) on similar topic in the study area was also major problems in this study.

Conclusion

The study identified that the HBC activities that were performed by VHC givers in the study areas limited in range. The common types of care that were provided in the study areas are physical and environmental care of the PLWHA, such as cleaning patients' body (body-bath, hair and nail care), cleaning the house environment, preparing food and feeding the patients, follow the patient to take ordered medications on time, provide advice, change patient's position on bed, refer to hospital for medical care, and some times provide dead body care.

The reasons for the provision of limited range of care were:

- Lack of adequate resource;
- Inadequate HBC training, specifically lack of medical and counseling knowledge and skill;
- Lack of support from health professional, community, government, and Kebele
- Time shortage due to absence of free or affordable transport service and work (patient) load
- The socioeconomic problems of the patients and their families;
- Stigma and discriminatory behavior of few health staffs and some community members to wards PLWHA and home caregivers;
- Absence of work relationship and integration of services among home care organizations as well as other community health care services
- Lack of adequate support for CVHBC givers
- Lack of adequate health care infrastructures including referral system.

Recommendations

Based on the above conclusions the following recommendations are made to the care and support organizations, planners, and policy makers:

- 1- There is a need of adequate medical equipment and trained home caregivers (manpower) for HBC program
- 2- There is a need of providing adequate HBC training that include initial, on-going, and further training for home caregivers
- 3- There is a need of adequate support from all stakeholders (materials, psychological and professionals support)
- 4- There should be adequately functioning health care infrastructure that includes formal referral policy that strengthening the referral system between home care and health facilities (include free or affordable transportation service based on health facilities as well as HBC for PLWHA).
- 5- The government must implement poverty reduction programs in collaboration with community members through establishing income generating activities and micro-credit (that include waiver fee for medical care services in health facilities). These programs must be prioritized and organized to ensure that those in most need are helped first.

- 6- There is a need of continuous community awareness' raising program through health education about the transmission and prevention of HIV/AIDS and the advantage of HBC, in order to reduce communities' stigma and discrimination, and to promote community participation.
- 7- There is a need of work relationship and integration of health services among Home care organizations as well as other community health services in the area.

Further more, the relevance of the program to the community and national needs recommends them for policy recognition & inclusion, to increase internal funding and further strengthen their capacity to improve on their sustainability, efficiency, and effectiveness.

Finally, it recommended that there is a need of further studies with a combination of quantitative and qualitative methods by included the important stakeholders that related with HBC services such as CVHBC givers, Health workers, NGOs that implementing HBC, and PLWHA.

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Annex-2 : Questionnaire and data collection format

Assessment of CVHBC for PLWHA in Nazareth town, Ethiopia; 2006.

Consent format for In-depth interview questions.

Introduction:-

Welcome to this interview

My name is -----and my colleague name is -----.We are here to collect information about CVHBC for PLWHA. Its aim is to study about the experience of CVHBC givers in HBC of PLWHA and to identify the major challenges in HBC in order to suggest possible solutions for improvement of the program.

Now we ask you some questions about HBC of PLWHA that you answer according to your knowledge and experience. There is no right or wrong answer. All comments, both positive and negative are welcome. We would like to have many points of view and to be open interview, so feel free to express your opinion honestly and openly.

Your name as well as address is not recorded in this interview to protect your confidentiality. You have also the right to answer or not for questions which might be inconvenient for you. However, your information is very important to evaluate and improve the program. Again, we would like to confirm to you that all your comments are confidential and used for research purpose only.

Therefore, are you willing to participate in this interview? (YES or NO)

If no, thanks her/him and stop in here.

If yes, thanks her/him and continue the next questions.

Date of interview: _____

Time started: _____ Time ended: _____

Interviewer name: _____ Sig. _____

Reporter name: _____ Sig. _____

Supervisor name: _____ Sig. _____

I- In-depth interview questions for home care team: Semi-structured interview guide.

- 1- Would you describe what HBC mean?
- 2- Describe the range of Home care activities that performed by VHC givers?
- 3- Describe how you conduct HC of PLWHA in your community?
(Probe: approaches, range of care, referral process)
- 4- Where do referrals of patients come? (How well are these working? What can be done to improve the referral system?)
- 5- Medical care of patients- the content, appropriateness, and adequacy of home care kit; adequacy of medical care knowledge.
- 6- What are the sources of care and supports for HBC in your community?
- 7- How well the partnership working? (NGO/Government home care team/ medical facilities)
- 8- How do you see the linkage with, and support from other programs (food aid, micro-

credit)?

9- What are the major problems you encountered during the provision of HC for PLWHA?

10- What things are important in helping you do your job well?

11- What do you suggest to improve the HBC program?

12- Would you have any questions or suggestion to ask or to add?

Consent format for focus group discussions.

Date of FGD: _____

No. recruited for FGD: _____

Venue: _____

Time started: _____ Time ended: _____

Facilitator/moderator name: _____ Sig. _____

Introduction:-

You are all welcome. First of all we happy that you could make time to us. We are here to collect information about CVHBC for PLWHA. Its aim is to study about the experience of CVHBC givers in HBC of PLWHA and to identify the major challenges in HBC that help to improve the quality of HBC provision for PLWHA.

You have been purposively selected to participate in this discussion because we believe that, you are one of the key informants in this community, and also you have vital information and experience to share with us on this subject.

There is no right or wrong answer. All comments, both positive and negative are welcome.

We would like to have many points of view and to be open discussion, so feel free to express your opinion honestly and openly.

In order not miss any point of the discussion; we use a tap recorder. Your name as well as address is not recorded in this interview to protect your confidentiality.

Individuals are free to decide on whether or not to participate in the discussion. We also encourage members to feel free to say any thing concerning the topic of discussion, because your information is very important to evaluate and improve the program. Again, we would like to confirm to you that all your comments are confidential and used for research purpose only.

Thank you very much again. (The facilitator asks participants to introduce themselves at this stage and then introduce your self.)

Open-ended interview guide questions for FGDs

1- Would you describe the range of home care activities that performed by CVHC providers for PLWHA in your community?

Probe:-

Would you explain further?

Would you give us an example?

Is there any thing else?

2- What are the sources of care and supports for HBC in your community?

Probe:-

Would you explain further?

Would you give us an example?

Is there any thing else?

3- How do you describe the linkage with, and support from, other programs?

Probe:-

Would you explain further?

Would you give us an example?

Is there any thing else?

4- How well the partnership working? (NGO/Government home care team/ medical facilities)

Probe:-

Would you explain further?

Would you give us an example?

Is there any thing else?

5- What constraints do VHC givers encounter as they provide care for PLWHA at home?

Probe:-

Would you explain further?

Would you give us an example?

Is there any thing else?

6- Do you think VHC givers need more information about how to care for PLWHA?

(If yes, what kinds of information? What is the most urgent need?)

Probe:-

Would you explain further?

Would you give us an example?

Is there any thing else?

7- Do you any suggestions on how the work of the VHC teams can be improved?

8- Are there any other comments that any one of you would like to make about taking care of PLWHA?

THANK YOU!