EXPERIENCES AND PERCEPTIONS OF PEOPLE LIVING WITH HIV AND AIDS UNDER THE COMMUNITY HOME-BASED CARE PROGRAMME IN BOTSWANA

NJOKU O. AMA

BACKGROUND

Botswana, with HIV/AIDS prevalence of 17.1%,1 is one of the worst hit countries in the sub-Saharan region and the world. This figure shows a significant drop from the adult prevalence rate of 37.3 percent at the end of 2003 when 330,000 adults were known to be living with the disease and with about 33,000 recorded deaths due to AIDS.2,3

Botswana has a good health care system that is evenly distributed across the country and very supportive of most of its sick citizenry. Formal health care for HIV and AIDS clients is provided at the health facilities (hospitals, clinics, community and local health posts) at virtually no cost. As the number of people living with HIV (PLHIV) and AIDS increased, it became increasingly difficult for health facilities to offer formal care. The community home-based care (CHBC), a model of health care delivery for people living with HIV/AIDS and their siblings was, therefore, instituted by the Government of Botswana in 1995 as a measure to decongest the health facilities. Community mobilization was adopted as the major strategic intervention of the CHBC programme in recognition of the shortage of skilled human resource within the government health facilities to deliver CHBC. Volunteer caregivers, (who are not paid) mainly others, such as, lovers, spouses, friends or family of someone with AIDS, provide practical help and nursing care at the home of the clients. They are not professional care providers but the services they provide, though restricted, save the government huge expense. These volunteers visit the home of sick people and give basic nursing services, counseling, health education, nutrition monitoring and some psychosocial support while taking precautions to prevent the spread of HIV. The volunteers are usually recruited from

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the communities and trained on basic principles of care giving including nursing care.

The community home-based care is rooted in the principle of preservation of traditional caring patterns which encourages families to take responsibility for the sick members. Care for clients with HIV/AIDS in the home enables families (primary care givers) and communities to be actively involved in their care. Traditionally, parents, spouses and adult daughters have been caregivers to people with terminal illnesses. Some of the basic nursing services rendered include cleaning of wounds, treating of sores, mouth care, turning the clients to lie on other side, assisting the clients to visit toilet and visiting health facilities to obtain medication and reminding clients to take medication. The volunteers assist the families of clients through training in basic skills, especially on how to grow vegetables and to become primary caregivers. Social workers assist in securing food baskets and welfare benefits by liaising with or refer to welfare officers.

The greater numbers of people who receive home-based care are the elderly or terminally ill clients. With the increase in the incidence of HIV/AIDS, however, the number of people desiring home-based care has increased tremendously and now includes young people and their families. The level and quality of support, however, depends on the health status, ability and competence of the caregivers (primary or volunteers), and the environment and support systems that exist within the environment.

In homes where there are no family members, the volunteers become primary care givers to the clients, assisting in cleaning the homes of their clients, washing, cooking and doing other household chores. The volunteers sometimes spend their own money to provide food for the clients or transport the clients to health facilities to consult the doctor and collect their medication.

Recruitment of a client into the Community Home-Based Care (CHBC) Programme in Botswana follows a process of recommendation from the medical doctor handling the case of the client to the Social Welfare Officer (usually a trained nurse). The Social Welfare Officer prepares documentation on the client and forwards this to the CHBC Coordinator at the community level, who assigns caregivers to the client. The client is further enlisted for food basket and for additional care by the nurses in the clinic closest to the client’s home.

PLHIV/A have been known to go through a lot of trauma right from the time they are tested and known to be positive. Such trauma are associated with the stigma that goes along with the disease, and include negative words and phrases used by people in the community to name the disease, most of which have negative implications; physical, verbal abuse and neglect; sexual exploitation and abuse by men; physical violence and victimization in relationships; some women face rape by HIV-positive husbands who know they are HIV-positive; and poor access to health. As they are referred for care giving under the CHBC Programme, they go through additional experiences and have certain perceptions about the care they receive. These experiences and perceptions are hardly expressed by the clients, and are therefore, hardly addressed by CHBC programme developers, health and social care decision makers. An analysis of these experiences and perceptions of PLHIV in a CHBC programme will assist programme and health care planners in developing appropriate interventions to mitigate the adverse conditions of PLHIV.

Thus, this study was carried out with the aim to inform policy makers on intervention measures to improve the life of people living with HIV and AIDS.
METHODOLOGY

This study supported with funding from the Office of Research and Development, University of Botswana, has addressed the experiences and perceptions of PLHIV/AIDS drawn from 4 health districts (2 urban and 2 rural) in Botswana. It assessed the type of support the clients received, the client’s assessment for inclusion into the CHBC programme. Factor analysis was used to identify the most significant psychosocial and emotional feelings the clients go through in receiving care from caregivers (primary and volunteer).

The study was cross-sectional, using quantitative methods in obtaining information from the caregivers. A three-stage stratified sampling method was used. The health districts, community home-based care groups and clients constituted the three strata. Four health districts (2 urban and 2 rural) were randomly selected from the list of 16 urban and rural districts (4 urban and 12 rural) that had established community home-based care groups.

From each of the 4 sampled health districts, two Community Home-Based Care groups were randomly selected. Because of the stigma associated with HIV and the non disclosure of HIV status, it was not possible to obtain a sampling frame for the clients. The study relied on the goodwill of the caregivers of the clients and the Community Home-Based Care Coordinators in reaching the clients. The households where the clients lived were identified by the caregivers. A systematic random sampling method was then used in selecting the household for the study. The caregivers travelled with the Research Assistants to conduct interviews at the homes of the clients, although they had to recuse themselves during the interview.

The study answered the following questions:

i. What kind of support was available to the clients and who provided the support?

ii. When clients were referred to Community Home-Based Care, how long did the process take and how satisfied were clients with the process?

iii. What type of assistance did clients receive from the caregivers?

iv. What were the psychosocial and emotional feelings about the clients’ health conditions?

v. Were the clients satisfied with the services they received from caregivers?

Setting and sample

The study was conducted between June and September 2008. It covered Gaborone, Kweneng East, Selibe Phikwe and Bobirwa health districts in Botswana and eight sampled community home-based care groups (two groups from each health district). A total of 83 clients were interviewed from the four health districts as shown in Table 1.

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>Number of clients interviewed in each health districts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health district</td>
<td>Number</td>
</tr>
<tr>
<td>Bobirwa</td>
<td>25</td>
</tr>
<tr>
<td>Gaborone</td>
<td>18</td>
</tr>
<tr>
<td>Kweneng East</td>
<td>9</td>
</tr>
<tr>
<td>Selibe Phikwe</td>
<td>31</td>
</tr>
<tr>
<td>Total</td>
<td>83</td>
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The research instrument used in this study was the questionnaire developed by the authors, drawing experience from relevant literature. The questionnaire contained questions about the clients’ demographic characteristics; their opinions on the type and provider of support they received; the referral process into the CHBC programme; the type of assistance they received from caregivers; and their psychosocial and emotional feelings about their health conditions. Answers to some of the questions were provided on a five-point scale; in other cases, the questions...
were open-ended and gave the clients an opportunity to express their own opinions on a number of issues.

The questionnaires were administered to the clients by trained Research Assistants, who explained to the clients the purpose of the study, that participation was voluntary and that they can withdraw from participating at any time. The clients were assured of confidentiality of information obtained. Following these explanations, the clients who were willing to participate signed a written consent form.

The questionnaire and protocol for this study were scrutinized by experts in the Departments of Statistics and Nursing Education, while staff of the Community Home-Based Care department of the Ministry of Health, Botswana, assessed the protocols for the use of appropriate terminologies and sample to be studied. Finally, the protocols were approved for use by the Health Research Unit (HRU) of the Ministry of Health, Botswana. The questionnaire was later tested on a sample of eight people living with HIV/AIDS from a Community Home-Based Care group in Gaborone different from those that were studied for content validity and quality, before being used for the main study. The Cronbach alpha was calculated as 0.90.

Limitations of the study

There are several limitations to this study. The study covered only eight community home-based care groups selected from four health districts in Botswana. Although appropriate methods were used to collect the data, the study is, however, limited in scope. Because of the stigma associated with HIV and the non disclosure of HIV status, it was not possible to obtain a sampling frame for the clients. The study relied on the goodwill of the caregivers of the clients and the Community Home-Based Care coordinators in reaching the clients. All the analyses in the study have been made on the assumption that the information provided was accurate and reflected the true perceptions of the clients. The author acknowledges that results of the study is based on respondents’ information from eight CHBC groups selected from four health districts. Interpretation of the results are, therefore, limited to the studied areas, but the results do provide strong reasons for extending the study to other CHBC groups in the country.

RESULTS

Characteristics

The study showed that 64 percent (n = 53) of the clients were female while 36 percent (n = 30) were male. While 47 percent (n=39) had no educational qualifications, 52 percent had some educational qualifications. Majority of the clients (87%) earned below P 2000.00 (or equivalently US $ 263.00) monthly. The mean age of the clients was 50 years.

Perceptions on the type of provider and support

The clients were asked “How do you meet your ‘needs’ for food, clothing and day to day necessities?” “Who provides you the support?” The clients’ responses show that 61 percent had their needs met through relatives while 29 percent had their needs met through their salaries, and 25 percent, through caregivers’ support. Majority of the clients (89%) received emotional support from both the primary and volunteer caregivers, while 66 percent received psychosocial support, cleaning of the environment (47%), financial (46%) and 35 percent received clothing. Only 34 percent indicated they received medical support. The analysis further showed that more clients from the urban districts received emotional and financial support and less psychological support than those from the rural districts.

Seventy-six percent of the clients believed that family members provided
the best support followed by the volunteer caregivers (17%). Only 2.4 percent of the clients felt that neighbours and health workers provided the best support.

Two out of every five clients (40%, n=33) indicated that they were ever visited by a nurse at their homes. The visits were sporadic, sometimes once or twice in a week (10%) or once in a month (15%). Of those who were visited, 61 percent said the nurses only talked with them, 55 percent said they provided them health education while only 16 percent indicated that the nurses provided hands on care. Help from social/health workers was also rare. Only 27 percent of the clients ever received any help from the social workers. Supply of food basket was only monthly. Only 24 percent of the clients received it while about 76 percent said they never had any supplies.

An overwhelming proportion of the clients (92%) went for their regular check-ups but were mostly dissatisfied with the level of treatment they were given; either the drugs were out of stock, or had some side-effects and therefore, could not offer the necessary relief to the client’s ailment.

**Referral process**

A little over fifty percent of the clients (55%) indicated the referral process for enlistment into the Community Home-Based Care programme was completed within a month while the referral for about one-fourth of the respondents took between one to two months (Figure 1). Overall the mean time to complete the referral process was 39 days and 81 percent of the clients had their transfer process completed within the first two months.

The majority (83%) of the clients was satisfied with the time taken to process their referral for community home-based care and other services rendered. However, for the proportion of the clients (15%) who were not satisfied, some felt that the process took too long, yet others were of the view that the procedure was complicated and feedback to clients took long to come.

**FIGURE 1**

Percent clients who took the indicated number of days to be assessed and referred for CHBC
Assistance received from caregivers

The clients received assistance from the caregivers mainly in four areas: encouragement (82%), keeping company (80%), counseling (73%) and health education (69%). However, between one in every three clients to two in every five indicated that the caregivers did run errands; fetched water; prepared meals; collected drugs for them from the clinics; walked in the heat of the day to assist them and arranged access to food parcels and other materials. Staying awake to attend to the clients, bathing the client and washing their clothes were not priority areas of assistance by the caregivers (Figure 2). The clients’ responses also revealed that more clients from the urban districts than the rural districts received assistance from the caregivers. For instance, while 61 percent of clients who enjoyed the assistance of caregivers keeping them company were from the urban districts, only 20 percent of clients who enjoyed the same service were from the rural districts. Similar trends were observed in the responses of clients in the areas of receiving encouragement (urban-63%, rural-20%), counseling (urban-61 percent, rural-12 percent) and health education.

Over sixty percent of the clients were satisfied with the level of care given to them in the areas of keeping company, providing encouragement, counseling, health education, while over two in every five clients were satisfied with care received in arranging access to food parcel and other services, walking in the heat, preparing meals, bathing the clients, running errands, fetching water and financial support (Figure 2).

FIGURE 2
Proportion of clients who received assistance from caregivers and level of satisfaction with the care given
Psychosocial and emotional feelings

The clients were asked to indicate some of the feelings they had with regard to their health condition. Their opinions are shown in Figure 3. The figure shows that majority of the clients (84%) were completely overwhelmed by the state of their health while 82 percent of them experienced headache, stomach ache and common cold very regularly. A little over 70 percent (74%) were anxious about the effect of the ill-health on their resources, felt they were trapped by the ill-health (72%) or had difficulty in keeping their mind out of their ill-health condition (72%). The interference of ill-health with social relationships and difficulty in making decisions were some of the other expressed feelings by about 69 percent of the clients.

Factor analysis was used to understand the psychosocial and emotional experiences of the clients (Table 2 & Figure 3). The results show that most of the psychosocial and emotional feelings of the people living with HIV and AIDS are based mainly on community rejection (Factor 1). The majority of the variables are heavily loaded on this factor with correlations of 0.99. The second factor is the social status (Factor 2) and the correlations between the variables and this factor is between 0.84 and 0.92. The third factor is fear of eminent death while the fourth factor is economic status. The highlighted values in Table 2 show the correlation between each variable and the factors on which they are heavily loaded. The closer these values are to +1 or -1, the higher the degree of association between the variables and the defining factor.

FIGURE 3

Clients' perception of psychosocial and emotional feelings associated with HIV/AIDS condition
The experiences and perceptions of people living HIV and AIDS with regard to care giving in this study have been examined based on a random sample of 83 clients drawn from 4 districts (2 rural and 2 urban) in Botswana. The findings that majority of clients had their basic needs met by relatives and relatives provided the best support to people living with HIV and AIDS followed by caregivers (volunteers) are very supportive of earlier statements.
that care giving is usually carried out by family members. Ncama puts it this way, “Families are the central focus of care and form the basis of the Community Home-based Care team. Programme on community home-based care need, therefore, to examine ways of supporting relatives of HIV/AIDS clients to become more effective in the care of their sick relatives”.

The study showed that visit by nurses and social workers from the clinics were sporadic and sometimes some clients were hardly ever visited. Even when the nurses visited, majority of the clients indicated that they only talked with them neglecting their principal responsibility of hands on care. One of the core dimensions of home care is nursing aids and hygiene which are best provided by trained nurses and social workers. Supervision of primary and informal caregivers constitutes one of the ingredients of the Community Home-Based Care programme and is best provided by trained nurses, social workers and trained members of the CHBC team. These components were lacking among the services provided by the nurses and social workers.

Although over 90 percent of the clients made their routine calls to the clinics to collect their drugs but the study showed that the clients were dissatisfied with the level of treatment they were given; either the drugs were out of stock, or had some side-effects and, therefore could not offer the necessary relief to the client’s ailment. It is important that essential drugs necessary to treat illnesses most prevalent in the particular community, such as pain medication, basic treatment for opportunistic infections, some treatment for prevention of HIV, are available for the clients at the clinics. Correct diagnosis of the prevailing problems should be made and prescriptions explained to the clients or the caregivers to prevent over dose of drugs and subsequent side effects.

The study showed that the mean referral time from hospital care to community home-based care for the clients was 39 days (within the first 2 months). Although the results of the analysis showed that majority of the clients were satisfied with the referral process, yet some of the clients agreed that the referral time was very long. A process as crucial for continuum of care as this ought to take shorter time to conclude. It points to some lapses in communication between the hospitals or clinics and the Community Home-based Care teams at the surveyed districts and communities.

The major areas of assistance to the clients were encouragement (82%), keeping company (80%), counseling (73%) and health education (69%). Staying awake to attend to the clients, bathing the client and washing their clothes were not priority areas of assistance by the caregivers. These areas of neglect are some of the crucial areas where family members as caregivers are expected to deliver care. The neglect of these services to clients points to the weakness of the CHBC programme in the sampled areas and the lack of or inadequacy of training to family members and volunteers in care giving. The concentration of care for PLHIV in urban areas to the detriment of those in rural areas speaks ill for the CHBC programmes. Efforts need to be made to balance the care for PLHIV and their families in all communities. Sensitization of communities is essential to get them involved in caring for PLHIV.

The study has shown that being completely overwhelmed by the state of their health, experiences of headache, stomach ache and common cold, anxiety about the effect of the ill-health on their resources, feeling of being trapped by the ill-health and difficulty in keeping their mind out of their ill-health condition were the most prevailing psychosocial and emotional worries of the clients. In addition, psychosocial and emotional
conditions of the clients can be attributed to community rejection of the PLHIV, fear of imminent death, social and economic status. Community rejection of PLHIV has been one of the stigma among HIV positive people and has been known to make it difficult for people trying to come to terms with and manage their illness on a personal level. It also interferes with attempts to fight the AIDS epidemic as a whole. It can make individuals reluctant to access HIV testing, treatment and care.17-19

Feeling of loneliness, loss of resources and interference of the epidemic with one’s social relationships overwhelms the clients and represent some of the consequences of HIV-related stigma.20 Most people living with HIV/AIDS become HIV positive when they are most economically productive. The health problems translate into financial problems for them and their families. The loss of income due to job loss, sick time or inability to work in the family fields, combined with increased need for resources to keep them living, become a burden for the clients and their families.

CONCLUSIONS

In the light of the findings, the study concludes that since family members are key to providing care to PLHIV and AIDS, they should be adequately supported to provide this care. Such supports include training of family members on cleaning and dressing of wounds, oral hygiene, supervision of medication taking, pain management, diagnosis of opportunistic infections, counseling, information on HIV prevention, and material support to clients and their families.

Nurses and other medical personnel need to get more involved in the CHBC programme. Visit of clients in their homes should become more regular so as to observe the state of their health and supervise caregivers.

The Governments need to get more involved in the provision of essential drugs necessary to treat illnesses most prevalent in the particular community, ensure the availability of the drugs for the clients at the clinics. Doctors and nurses involved in treating people living with HIV and AIDS should ensure that correct diagnosis of the prevailing problems are made and prescriptions explained to the clients or the caregivers to prevent over dose of drugs and subsequent side effects.

Increased and more efficient communication between the hospitals, clinics and community home-based care groups are desirable to help reduce the referral time of the clients for CHBC.

Communities and families need to develop strategies to generate income for PLWHA. It is crucial to change community norms through well articulated education programme so as to reduce the stigma surrounding HIV and AIDS and ensure human rights. Furthermore, communities should develop action plans to support families in caring for the client and themselves. Such support plans might include growing of vegetables and financial contributions to the families of client through fundraising programmes.

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REFERENCES


