

Community Responses to HIV/AIDS: The role of volunteers in home-based care for people living with HIV/AIDS in South Africa

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INTRODUCTION

The HIV/AIDS epidemic is having a deleterious impact on the social and economic development of the most affected countries. Sub-Saharan Africa is home to 70% of infected persons worldwide. In South Africa, 20.1% of the population is either infected with HIV or living with AIDS (UNAIDS, 2002). KwaZuluNatal is the worst affected province in South Africa with a prevalence rate of 36.2% (DOH, 2001).

HIV/AIDS is the leading cause of death in many sub-Saharan Africa countries including South Africa (UNAIDS, 2002). According to Dorrington et al (2001) HIV/AIDS accounts for between 25%-40% of deaths in South Africa. Although HIV/AIDS affects all sectors of the society, studies have shown that the most severe effects occur at the level of the household and communities (UNAIDS, 2000a; Barnett and Whiteside, 2002, Akintola, 2004b). According to Loewenson and Whiteside (1997), the household impact of HIV/AIDS has three stages, namely illness, death and the longer-term consequences of AIDS morbidity and mortality. Stover and Bollinger (1999) have documented a range of potential impacts on households, which include the loss of income (originating from reduced labour supply within the household or from lower remittances of the person with HIV/AIDS, who is usually the main breadwinner); increase in household expenditures for medical expenses; decrease in household savings; permanent loss of income, as a result of death or loss of a job; increase in funeral costs; the removal of children from school in order to circumvent educational expenses; and other members of the household, usually daughters and wives, may miss school or work in order to take care of the sick.

Furthermore, there is evidence to suggest that the provision of care for people living with HIV/AIDS accounts for a substantial part of the household and community burden of HIV/AIDS and that the informal caregivers carry a substantial part of the burden (UNAIDS, 2000, WHO, 2000, Barnett and Whiteside, 2002, Akintola, 2004a). The cost of caring for people living with HIV/AIDS is enormous and difficult for affected families to carry alone. Recent studies by Johnson et al (2002) in South Africa showed that HIV/AIDS affected households spent 34% of their monthly income on healthcare compared to the average of 4% spent by households in the country. Yet many of the people living with HIV/AIDS are dying and may not necessarily benefit from continued hospitalization but need palliative care and support¹. Meanwhile, many government

¹ Patients in the third stage (full blown AIDS) of the CDC 3-stage diseases classification who are not on antiretroviral therapy may not get any better when hospitalized and would need family support which is not often available in formal health facilities. Moreover, Uys (2003) found a significant relationship between

health facilities do not have the capacity to cope with the large numbers of people living with HIV/AIDS (PLWHAs) that daily seek care (DOH, 2001, Akintola, 2004b). In view of this, the South African government issued a national guideline on home-based care in 2001, which was intended to serve as a guide for the promotion of home-based care in the country (DoH, 2001). Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards dignified death² (DOH, 2001). Consequently, there has been an increasing shift from hospital care to home-based care for PLWHAs in the country occasioned by an increase in the 'dehospitalization' of HIV positive patients from formal health facilities (Akintola 2004a). This has tended to place the primary responsibilities for the care and support of the sick on the immediate families and communities (Akintola, 2004a). However, many affected households are ill-equipped to offer home-based. Yet a recent study conducted in four South African provinces showed that only a few households get any kind of support from government for home care and terminally ill AIDS patients are usually discharged from hospitals but unable to access palliative and terminal care and support (Steinberg et al, 2002). Thus in many of the affected communities, community based organizations (CBOs) have stepped in by mobilizing, recruiting and providing training for community members who volunteer their services. These volunteers in turn assist households and communities to relieve the burden of caring for people living with HIV/AIDS.

Although some of these volunteer programmes have been documented, none have focused specifically on the role played by volunteer caregivers in home-based care for people living with HIV/AIDS (PLWHAs) in their communities. Yet these volunteers form the backbone of many community care programmes in South Africa (Akintola, 2004a). Thus this study was carried out to understand and document the role that volunteers play in mitigating the burden of HIV/AIDS care in households and communities.

OBJECTIVES:

This study set four objectives as follows:

- To explore and document volunteer's understanding of volunteering in the context of home-based care for PLWHAs and their motivations for volunteering.

dying at home and having a good death suggesting that many HIV/AIDS patients prefer to die at home. Palliative care has been defined as the combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life threatening illness. It aims to improve the quality of life at the end of life by relieving symptoms (especially pain) and enabling people to die in peace with dignity and in keeping with their wishes (WHO, 2002).

² According to the guidelines, home care services can be classified into preventive, promotive, therapeutic, rehabilitative, long term maintenance and palliative care categories. It is an integral part of community-based care. Community-based care is the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities (DOH, 2001).

- To explore and understand the role that volunteers play in home-based care for PLWHAs.
- To understand and describe the source(s) and nature of support available to volunteer caregivers.
- To understand and document the challenges and needs of volunteer caregivers?

METHODS

Study Context and Setting

This study was conducted among volunteers working with Sinosizo Home-based Care Programme based in Amazintoti on the outskirts of Durban. Started in 1995, Sinosizo is a flagship programme of the Catholic Archdiocese of Durban AIDS Care Commission and it is registered as a non-governmental, not-for-profit organization. Sinosizo is a Zulu word for 'we help'. The programme operates in eight communities which include urban and rural townships as well as informal settlements in the Durban metropolis (Personal Communication, Madden, 2004).

The study was conducted among volunteers working in four of the communities serviced by Sinosizo home-based care namely: Lamontville, Groutville, Etete and Siyanda. Lamontville is a township approximately 15 Kilometres South of Durban with good tarred roads and access to electricity and water. Etete is a rural community approximately 50 kilometres North of Durban. Most of the houses are made of wood and iron, mud and shacks but some are made of bricks. Groutville is located approximately 58 Kilomteres North of Durban. Most of the houses are made of bricks but some live in shacks. Many have access to electricity and water is supplied through communal taps located close to dwellings. However, most of the roads are dirt roads and access is difficult in wet conditions. Siyanda is an informal settlement and until recently, not a single house had electricity. Houses do not have water or toilets but residents make use of stand pipes and pit toilets. All the four communities are inhabited by Indian Coloured and African people. However, Siyanda, Groutville and Etete have immigrants from other Southern African countries.

At the outset, members of the communities are recruited as volunteers from the Catholic Church but currently, volunteers are being recruited with the help of councilors and community leaders. They are thereafter trained and sent into the affected homes as home-based carers.

Study Participants and Methods of Data Collection

This is an exploratory and descriptive study. A qualitative research approach, which explores a range of perspectives around the research questions, was used to answer the research questions due to the sensitive nature of the subject and dearth of knowledge on the issues to be investigated (Shears, 2002; Strauss and Corbin, 1998).

The first step in the research process was to approach the gatekeepers. I sought and obtained permission to conduct the study from the management of Sinosizo Home Based Care. At the outset, unstructured interviews were held with key informants such as the Project Manager of Sinosizo Home Based Care, the project nurse as well as the community coordinators of the volunteer caregivers. These people were interviewed because of their wealth of experience in working with volunteers. The information obtained from the key informant interviews as well as an extensive review of literature was used to develop instruments for the focus group sessions and the in-depth interviews that followed.

The Project Manager also assisted in identifying communities in which Sinosizo home-based care was active. Four of these communities namely Lamontville, Etete, Groutville and Siyanda were selected to reflect a wide range of perspectives on volunteers' socio-demographic characteristics as well as caregiving experiences. Factors such as accessibility of the communities and willingness of the volunteers in such communities to participate in the study were also used as criteria for choosing the communities. The Project Manager thereafter arranged meetings between the researcher and facilitators of the volunteer caregivers (VCGs) in each of these four communities. Afterwards I, in consultation with the facilitators, in turn arranged meetings with the volunteers. At these meetings, the aims of the study were explained to the volunteers and questions and concerns addressed. They were also given a verbal guarantee that any information offered will be kept anonymous and confidential and that participation in the study was voluntary. Volunteers who indicated their willingness to take part in the study were then invited to participate in focus group sessions and in-depth interviews. An appointment was also made with those who indicated willingness to participate in in-depth interviews.

One major criterion for inclusion in the study was that participants must have been working as volunteers in that community for at least 6 months. This was deemed necessary in order to ensure that participants had some caregiving experiences to share during the focus group sessions as well as interviews.

A focus group discussion schedule was developed using information from the key informant interviews. Four focus group sessions were held with each group consisting of 6-8 persons. Each focus group was moderated by the researcher and field assistants and discussions were tape recorded.

Face-to face in-depth interviews were conducted in each of the four communities by the researcher and trained field assistants. Participants in the focus groups and individual interviews were requested to give verbal informed consent before the study was conducted.

In-depth interviews were conducted with volunteers using an interview guide consisting of open-ended questions developed with information from key informants and focus groups. This guide covered topics such as socio-demographic characteristics of volunteers, motivations for volunteering, type of care provided, effect of care on other activities, support received, support needs, coping strategies, problems with caring and

suggestions on what could make their work easier. Interviews were conducted in such a way as to allow respondents to raise issues and themes previously unanticipated (Shears, 2002). Additional information on the Home Based Care Project, community profiles among others were also obtained from the records of Sinosizo Home Based Care.

Data translation and analysis was carried out concurrently with data collection. This was done in order to get feedback from the data being collected and to add new and pertinent information that was raised to the instruments being used and adjust accordingly as the data collection progressed. The interview schedule was therefore constantly being reviewed. This was found to be very useful in eliciting a wealth of information from volunteers and other stakeholders.

Tape-recorded data was transcribed verbatim and then translated from Zulu to English by a translator. Analysis was done using the constant comparative method which is consistent with the grounded theory approach (Strauss and Corbin, 1998). Constant comparison was done by reading the data over and over again and grouping statements into themes. These themes were then grouped into categories and sub-categories.

FINDINGS

Socio-demographic characteristics

In all, 37 volunteer caregivers participated in the study all but one of whom are women. Their ages ranged from 22-50 years and almost all of the volunteers were of the Christian faith; largely members of the Catholic and Zion Churches. Only 4 of them were married, one was widowed³ and the others were single parents and heads of households, only one of the respondents said she did not have a child. About half were living alone with their children, some lived with their parents, and the remaining co-habited with their boyfriends. However, a few were living with their boyfriends. Most of them had between 10 – 12 years of education and were unemployed although a few were petty traders and some had part time domestic work while some were vendors. The generally high level of unemployment may be explained, in part, by the general lack of skills among the volunteers at the time of enrolment. Those of them who were unemployed at the time of the study stated that they sometimes get occasional employment as domestic workers.

The low level of men's involvement in volunteering was explored in focus groups in view of the preponderance of female volunteers. The women claimed that very few men are interested in giving care to sick people. Some of the reasons alluded to include the fact that women are the ones who give birth and that this makes women more compassionate than men:

I think it is because men do not have the heart. Yes I (once) had a case whereby a boy was taking care of his brother and when I came there, he ended up shifting the responsibility to me.

The assertion was that men provide care only when there is no women around to do it and that they look for every opportunity to abdicate the duty. The other reason relates to men's reluctance in touching women's body particularly the genitals. Female volunteers on the other hand claimed that they carry out examination on men's genitals for infection and even wash their private parts while bathing them without being embarrassed.

The low level of involvement of men in caregiving has been noted in other studies (WHO, 2000 & Akintola, 2004b). This finding should be explained in the light of prevailing norms on sexuality and masculinity in traditional African societies. Leclerc-Madlala (2000) offers an insight into the assertion made about men avoiding women's private parts. She discusses how men view women's bodies as dirty and bearers of disease. The only man who participated in the focus groups stated that there were only a handful of men on the volunteer programme. He indicated that although other men discourage them by make jest of them, he is undeterred:

They (friends and acquaintances) usually say that we (male volunteers) are doing women's jobs and I used to tell them that they are saying that because they do not know what they are talking about.

³ This woman lost her husband to AIDS and is herself infected with HIV

Understanding the concept ‘Volunteering’?

We found it appropriate to begin focus groups and interviews by finding out the participants’ understanding of the concept volunteering. Focus group and interview participants were asked to give their own definition of volunteering. Two major themes emerged in answer to this question. The most common theme relates to working without expecting a reward and the other is providing a service as a response to a need in the community.

‘Volunteering means working without pay’.

‘Ukuvolontiya ukusiza ungalindele nkokhelo’ (to help without expecting anything as a salary or profit).

‘*Ukuzinikela ekusizeni umphakathi* (is to offer your help or service to the community)’

‘*nanokubona isidingo sokuxhasa emphakathini esisuke sihlala kuwona kuwuzikela*’ (and is to see the need of filling the gap of a particular service to the community within which we live).

The most common definition given by all the participants however, is that volunteering means working without getting any payment in return. Other definitions relate to providing a service that fills a need within the community. It was clear from these responses that most of the participants had a shared understanding of what volunteering meant. This is probably due to the fact that volunteers are enlightened about the meaning of volunteering during the recruitment interviews. They are also informed of what it takes to be a volunteer. They are told that they will not be paid and must be ready to work from their hearts for the good of the community. It is at this stage that some of the intending volunteers who cannot work without pay drop out. Another possible reason is the fact that some of the volunteers were already involved in some sort of voluntary work in the community before being recruited into the programme. There seem to be a sense of community whereby participants felt the need to help others by ‘volunteering’.

What do volunteer caregivers do?

Volunteers carry out a wide range of activities among HIV/AIDS affected families in their communities. Their primary duty is to assist in relieving the burden that caring for PLWHAs has on the affected families. One of the major elements of care is that of showing compassion and love to the patients and also providing spiritual support by praying with them and encouraging them. The participants noted that this form of care is very important and central to the patient’s recovery. This is more so in the light of the fact that PLWHAs feel that nobody loves them⁴(Akintola, 2004).

Patient education carried out by volunteer caregivers covers the provision of information about HIV/AIDS/TB transmission and prevention, nutrition and positive living and alcohol abuse. The training that volunteers receive also enables them to provide basic

⁴ This reason for this assertion is explicated in the section on stigma and discrimination.

nursing assistance to the patients. These include pressure care, and wound care, skin and mouth care, massaging patients' body, infection control, guidance and support for adequate nutrition⁵. Volunteers teach families how to prepare oral rehydration solution for patients and also teach families how to prepare infant formulas for orphans. They also provide physical care by helping to turn or lift patients and managing incontinence by changing disposable nappies for the patients⁶. Patient assessment is done regularly and to find monitor the rate of recovery or otherwise of the patients. Those who need medical attention are then referred to clinics and hospitals for treatment.

Volunteers also assist patients to carry out their daily activities. These include feeding, bathing, dressing and walking. Some also assist with using the toilet and transferring patients. In instances where patients live alone and therefore do not have family members who could serve as primary caregivers, volunteers assist with household chores. They also assist with fetching drugs from the clinics and hospitals and in making sure that patients adhere to their regimen. They also help with Direct Observation Treatment (DOTS) for patients who are on TB drugs. In a particular Groutville and Etebe where Sinosizo recently started the roll out of antiretroviral treatment, volunteers serve as adherence monitors. Volunteers also help arrange transport to health facilities by calling the ambulance but when the ambulance does not show up, they arrange for neighbours or friends to transport the patients. Children whose parents were benefiting from the home-based care programme before they die are usually visited by volunteers to provide care and support.

Additionally, volunteers provide patients and their families with information on resources that are available in the community. They also assist them in preparing their documents for social welfare grants. The amount of time devoted to volunteering usually depends on the number of patients⁷ as well as the severity of illness of the patients. Other factors such as the needs in the home at the time of each visit also determine the length of stay. Nonetheless, volunteers spend an average of 3 hours per day and visit patients on average 3 times a week.

While volunteers are supposed to relieve HIV/AIDS affected families of the burden of care by teaching family members skills and knowledge on the various issues that relates to care outlined above, the practical needs of patients and their families compel them to go beyond this line of duty in practice; some of the volunteers become the primary caregivers in situations where the patients are living alone or neglected by family

⁵ Pressure care prevents the patients from developing pressure sores. Mouth care is carried out to clean thrush, a fungal infection common in AIDS patients.

⁶ The provision of disposable nappies was suspended because of lack of funds. Clothes and papers are now used as alternatives.

⁷ In order to reduce the burden on volunteers, the programme office has pegged the maximum number of patients that volunteers can have at any particular time at 5 full blown AIDS patients. Nonetheless, volunteers caring for walking well patients can have up to 20 patients. In Siyanda and other communities where the demand for home-based care is high, volunteers work for longer times and some work everyday of the week.

members as a result of discrimination⁸. Volunteers are also called in at any time of the day or night for emergencies, such as when a patient needs urgent attention. They are sometimes called in to settle disputes and fights among family members or when there is a domestic accident or for them to assist in calling the police or fire department.

Volunteers also play a central role when their patients die. As a result of the high costs of burials, volunteers try to ensure that their patients are admitted into the hospitals before they die so as to make certain that they will be given paupers burials. Furthermore, quite a number of their patients live alone without any family member, they therefore try to locate family members before or after the death of the patients and when they fail, they assist in burying the patients⁹.

Why do people volunteer to care for people living with HIV/AIDS?

An understanding of caregivers' motivations for volunteering is critical to understanding their role in mitigating the burden of caring for people living with HIV/AIDS. Participants were therefore asked to give reasons for volunteering to care for people living with HIV/AIDS. It was apparent from responses that there is a relationship between participants' definition of volunteering and their reasons for doing the job. As mentioned previously, volunteering is not new for some of the participants, particularly those in Lamontville. It started long before the advent of HIV/AIDS where community members were involved in volunteering to care for the elderly under the auspices of the Catholic Church. The Catholic Church in their community had set up a programme which addressed the needs of the elderly. Volunteers who enrolled on the programme visited the sick only once a month. Their primary tasks then were to visit the poor, sick and lonely and keep them company and encourage them spiritually using the Bible. What is new for such participants is the nature and magnitude of tasks that now had to be carried out. As the participants pointed out, caring for the elderly is a lot less demanding than caring for PLWHAs. Moreover, many of the elderly people were not sick but only needed spiritual counseling and moral support. Other participants were however volunteering for the first time and had a variety of reasons for doing so. The reasons given by both groups were varied and it should be noted that many of them had more than one reason. Caregivers' motivations are discussed under 2 broad themes namely pure altruism and personal reasons.

Altruistic reasons

⁸ Some family members deliberately shirk the responsibility of caring for family members, foisting them on volunteers. This point is explored further in the section on challenges faced by volunteers.

⁹ A particular instance where volunteers had to bury a patient because the volunteers could not locate family members was cited in one of the communities. In other cases when bodies are not claimed by family members, undertakers paid by government carry out paupers burials for unclaimed bodies.

Some participants cited mainly altruistic reasons for volunteering. These were mainly people who volunteered without hoping for any reward. The most common altruistic reason given across all the study sites is the need that has arisen as a result of the impact of HIV/AIDS on families, households and communities. Many of the respondents pointed to the fact that HIV/AIDS has infected many people in the communities and that those who fall sick sometimes do not have people to care for them and need some assistance, which one could not ignore. They therefore saw the need to assist the community members who needed help. Such needs are expressed in these statements:

‘I saw so many people becoming sick especially the young people they have been going to the hospitals and coming back home to die’

‘When we started people were dying like flies’

‘You see so many people are sick and they need some help’.

‘Other sick people don’t have families to take care of them’.

‘Some have family members who do not look after them’.

In some instances, family members who should provide care for the sick are also the breadwinners and have to go out to work leaving the patients alone without anyone to care. They also indicated that in instances where family members who could provide care are present; they usually lacked the requisite knowledge and skills needed.

They also pointed to the lack of response from government which has prompted them to do something about the situation. Their position is that they could not sit down watching people suffering and dying without doing anything to assist. A sense of community exists amongst those who volunteer thus people see themselves as their ‘brother’s keeper’. The narratives suggest a notion of abandonment by family members and government¹⁰. There is a general sense that people who need care are not being given the care they require hence the need for people who volunteer to care.

Although many of the participants were responding to a need in the community, there was a variety of factors that triggered them to volunteer. The experience of HIV/AIDS or, in a few cases, other chronic illnesses in the family was a common theme in many of the interviews. For these participants, their interest in volunteering was triggered by being affected:

My sister died and now I decided to do this job because I saw that there are so many orphans as a result of the disease

Another participant who had lost her child to HIV/AIDS related illnesses explained:

When my daughter was sick, I did not know what to do because I did not know anything about AIDS. I used to take care of her, wash her, and touch her without using gloves because I did not know anything about AIDS so when this opportunity

¹⁰ The issue of abandonment by family members and government is treated in greater details in subsequent sections.

of volunteering as home based carers came, I decided to take it so that I can help the sick people in my place. My child died because I could not help and I saw a need to stand up.

The physical and emotional pain that this woman, experienced in caring for her daughter put her in a better position to appreciate the plight of others in similar circumstances. Some others had previously lost someone to HIV/AIDS related illnesses found volunteering as a way of relieving their hurt. Many as stated above had indicated that they did not have the knowledge and skills to take care of their relatives when they fell sick. They believed that volunteering offered them another opportunity to provide proper care they couldn't do previously. Some also felt that volunteering could heal the wounds created by guilt of not taking proper care of their loved ones.

Some of the volunteers were living with HIV/AIDS and volunteering provides access to information about care and support and they are also able to access treatment for opportunistic infections¹¹. An HIV positive woman who recently lost her husband after caring for him for years and whose first son is also living with HIV/AIDS declared that she decided to volunteer because she 'knows how it feels to have HIV/AIDS and to be sick and dying'. Nonetheless, there were a few who had not experienced any HIV/AIDS related illness in the family but wanted to be prepared for it:

I want to get experience which I think is important. The knowledge we get from doing voluntary work becomes useful as well in our families especially when this disease strikes I will know what to do.

Personal reasons

Some participants cited personal reasons for volunteering. These include keeping busy, acquisition of knowledge and skills for use in family or for self, and the hope of a future reward or employment.

The high rate of unemployment in the study communities is a major reason why some volunteer. Many indicated that they were volunteering because of a lack of job or something to do. They also pointed to the fact that sitting at home doing nothing is not good for ones mental physical and mental health:

Volunteering keeps us busy. Yea I want to keep myself busy because there are no jobs and we are sitting at home doing nothing'

Volunteers who belong to this category continue volunteering until they get a job. For them therefore, volunteering is a means to an end. However, findings suggest that it is not

¹¹ In 2004, Sinosizo started the roll out of antiretroviral therapy for their patients and volunteers have also benefited from it. Information obtained from recruitment interviews shows that about 95% of people who volunteer are either infected or affected by HIV/AIDS. Some have had to care for sick close or distant relatives or neighbours while some have had to care for orphans left by relatives. Others are neighbours to affected families and have had to offer a helping hand at one time or another.

always easy for such volunteers to quit the programme. This is because they usually find the hands-on experience interesting and develop a deeper liking and attachment to the job. They suggested that they will be happy to continue volunteering on a part time basis should they get a paid job.

Many of the volunteers who had earlier cited the need to help others as reasons for enrolling in the volunteer programme had some other underlying reasons such as acquisition of some knowledge, skills and experience. These, they believe, will put them in a good stead to get a job in the future. For these volunteers, therefore, the decision to volunteer was due to more than one reason. These volunteers indicated that a combination of some of the reasons already discussed had led them to offer their services to the communities:

The first reason I do it (volunteering) is because I like it, it gives me more knowledge and information. Second, it keeps me occupied and busy. Secondly, I believe it channels me to the right paying job. Another thing is that the knowledge I am getting now becomes important to me and my family now and in the future.

Others believed that the knowledge, skills and experience acquired would come in handy should any member of the family fall ill.

Although some people show up for recruitment interviews but drop out voluntarily before the training starts because they cannot work without pay or cannot cope with the nature of the volunteer work, some others wait to be trained before dropping out. There is evidence to suggest that this is done strictly for personal reasons. The reason for attrition among those who had already received some training is the serious need for information on HIV/AIDS prevention and care in the affected communities. This suggests that some of the volunteers have a hidden agenda which they do not disclose when they are being recruited. They receive training on home-based care and then proceed to use the knowledge and skills acquired for themselves or members of the family without joining the volunteer programme. This phenomenon suggests a great area of need for information among community members which should be addressed.

SOURCES AND NATURE OF SUPPORT RECEIVED BY VOLUNTEERS

The attitude of the affected families and communities were explored in order to understand sources and nature of support and how these influence volunteers' performance of their tasks. Volunteers claimed that many of the community members held positive attitudes towards them and their work and do provide assistance when the need arises. Some cited instances where neighbours assisted in bathing patients and providing food when they got to know that the patients' children were crying due to hunger. Participants also stated that they receive support from their community leaders and councilors who facilitate their work in the community by assisting to create awareness. In addition, volunteers stated that the programme office gives them some token of appreciation in the form of gift vouchers and presents for their children in the middle of the year and during Christmas which gives their respective families 'temporary happiness'. They also claimed that they are given free treatment when they are ill and are

encouraged and appreciated with various kinds of incentives offered by the programme office.

In spite of these assertions, the general consensus was that many of the affected families and the communities in general did not provide support but instead held negative attitudes towards the volunteers and volunteering. Volunteers often cited the poor reception given to them by the patients' families when they visit them. Although they stated that this initial negative attitude usually changes after repeated visits and that some start to welcome them warmly.

An additional source of discouragement for volunteers is the negative comments made by community members. Participants described the concerns and discouraging comments of their family members, friends and neighbours. Some pass comments that suggest that they are irresponsible by 'leaving their children and going out to help other people without getting paid'. One said: 'some even call us fools' or call volunteering 'nonsense' and put pressure on them to quit. One volunteer described her experience with her neighbour:

She (neighbour) used to ask me whenever I am going out 'are you going to see your patients now' and I will say yes. And she will say 'when are you going to get paid' I'll just say, joking, 'I will be paid when I die or I will say I will be paid when you begin to give me 10c as my payment'. Then she will say 'I am not going to do that go and speak to your co-ordinator'.

She also claimed that her neighbour refuses to assist her when she needs some basic things like sugar but instead make nasty comments:

You are a Good Samaritan and you do not look for work and you are busy wasting your time with this voluntary thing of yours. So I do not have sugar for you.

One volunteer explained her plight stating that she usually left her child in the care of her neighbour when she goes out to visit her patients. Unfortunately, she is unable to pay the neighbour for her services since she is not employed in a paying job. But after a while, the neighbour got fed up of the fact that she does not pay for services rendered and also passes negative comments about her.

Although not a common occurrence, volunteers experience emotional stress when their patients and their families do not show appreciation but instead malign them. Some also bad mouth them when they refuse to carry out activities that are meant to demean them¹².

CHALLENGES OF VOLUNTEERING

This section details the challenges that volunteers face in the course of carrying out their duties.

Locating patients' homes

¹² This point is explored further in the section on over expectation from patients and affected families

Although some of the volunteers lived close to the homes of their patients, others had to walk long distances to get there. This put a lot of physical strain on them yet many remain committed and resolute to continue volunteering:

It is difficult to go to the patients' homes especially when it is raining or when the sun is too hot and you find that people need your help. ..but we have to go out even when it is hot, cold or when it is raining.

However, locating the homes of the patients during the first visit posed a huge problem. Participants, particularly those in large communities such as Groutville and Lamontville viewed this as one of the greatest problems they are confronted with. They were unanimous in stating that visiting patients' homes for the first time was not always easy and is, many times, an exercise in futility. This problem applied particularly to patients who were recruited through the hospitals:

When we (volunteers) get there (the addresses given by patients/clinics), we find that the person we are looking for is not there and nobody knows them or the house numbers we were given. Then we have to look for this person for the whole day and sometimes we return back home without having found the person

According to the participants, the problem usually arises because some patients give inaccurate addresses to the nurses in the clinics or hospitals. They believe that the fact that some of the patients are very sick at the time they are admitted to the hospital and the fact that many of the family members are illiterate could be responsible for this problem.

Another problem related to visiting patients is that some of the 'walking well' patients¹³ sometimes do not honour their appointments with the volunteers because they are not terribly sick, they do not see the need to wait at home for volunteers.

Expectations from Patients and Families

Family members of patients as well as the patients themselves often have unrealistic expectations from the volunteers. Volunteers claimed that many of the families are usually under the impression that the volunteers are paid by government to care for them believing that it is impossible for some people to volunteer to do such an arduous job without getting paid. Consequently, some families demand that volunteers do all the house chores and other caring activities for them because 'they are getting paid for it'. This has been a general source of conflict between volunteers and affected families.

Volunteers are often reluctant to go to the homes of some of their patients particularly those living in abject poverty because of high and sometimes impracticable expectations. Patients and their families usually expect the volunteers to bring them food and they ask questions like 'why did you not bring food with you'. And when they explain to them that the distribution of food parcels does not fall within the scope of their work, they develop a negative attitude towards them and some even ask them to stop coming to their

¹³ Walking well patients are those patients with symptomatic HIV but are not bedridden

homes. Additionally, some expect the volunteers to pay for their transport to the clinics and hospitals.

It was also stated that when patients die, the family sometimes expect them to come with some material gifts or money to assist them. These, participants claimed, puts them in a very difficult situation. They become shy having the feelings of inadequacy. One declared: 'we can not do anything more than what we have done when the person was still alive'.

Other expectations that patients and their families have relate to the scope of practice of the volunteers. Volunteers are not trained to administer drugs or injections, many therefore get disappointed when told that they cannot administer any drugs but only assist with basic nursing care.

Stigma and discrimination

Stigma and discrimination against people living with HIV/AIDS was very rife in all the four study communities. Participants stated that many of their patients are discriminated against by their families. One focus group participant said:

It was very shameful to the community; when you go and visit the people who have some sick family members they will tell you that there is no one who is sick in their house and if they happened to agree that there is they will ask you not to tell anybody about that

They asserted that affected families often chase them away even if the patient is willing to have the volunteers care for him/her.

Participants described the discrimination that many of the people living with HIV/AIDS in their communities experience at the hands of their immediate family members. Some of them are not given food to eat and made to go hungry, others are neglected and not taken care of, and some even put them in separate rooms or apartments and toilets specifically built for them. Some make them use separate plates which they destroy if it mixes with that of other family members. When volunteers offer to bath patients that have been neglected, their families discourage them by making negative comments such as 'you think you are better than us?' or 'you think you love him/her (the patient) more than we do?' This makes the volunteers feel bad and reticent.

Families also put the blame of contracting HIV on the patients. Some say: 'wawuwedwa ebumnandini sasingekho thina lapho' (We were not there when you were enjoying sex. You enjoyed it alone). Others attributed their infection with HIV to the fact that they 'did not listen to their parents'. This pattern of blame is generally used to discriminate against the patients and in many cases to avoid caring responsibilities.

The attitude of these families suggests a low level of knowledge about HIV/AIDS transmission. This position is affirmed by the fact that some of these families gradually

change their attitude with sustained education from the volunteers. Volunteers often stated that those families that rejected them initially have come to accept them eventually.

Whereas Stulberg and Buckingham (1988) point out that denial is not peculiar to AIDS but common to all terminal illnesses, it seems that the high prevalence of stigma in the communities creates fears about discrimination, which in turn exacerbates denial. Patients, in an effort to disguise their HIV status try to avoid contact with the volunteers because community members usually label persons visited by the volunteers as having HIV. There is therefore some stigma attached to being visited by the volunteers. To avoid this therefore, patients and their families sometime chase the volunteers away once the patients show some signs of recovery, claiming that the patients 'are feeling better and so they do not need their help any longer'

The fear of stigma and discrimination prevents people living with HIV/AIDS from disclosing their HIV status to other people including their family. When PLWHAs do disclose their status however, the families usually do not get to know because these patients mainly disclose to volunteers. This shared secret and the care that they provide strengthens their relationship and they become closer to the patients This leads to rifts between family members and the volunteers because the closeness makes them feel less important. They usually tell the volunteers Sizenza ngcono kunabo (we think that we are better than them).

The fears about discrimination are real than imagined and are constantly expressed by patients to volunteers who request for permission to disclose to their families. Such fears were expressed by a middle-aged woman with symptomatic HIV. She told me that she had only disclosed her status to the volunteer and that she was afraid to disclose to her daughter who was providing care for her because she is likely to blame her and abandon her stating that this was a common occurrence in the community.

Issues relating to physical and mental health

Volunteers mentioned the fact that their caring activities put a lot of physical strain on them resulting in body aches, back ache and commonly headache. Some indicated that they usually have headache, physical exhaustion and fatigue as a result of walking long distances to the patients' homes and others stated that the reason for their headache is the fact that they think about the health of the patient and their poverty and suffering. The other issue relate to the risk of infection that volunteers are exposed to. Although most of the volunteers have been taught about infection control and the use of protective devices when taking care of patients, one volunteer expressed fears that she may have contracted HIV. This concern stemmed from the need to cleaning up patients' vomits quickly:

What worries me is that if I have to do a blood test now I am likely to test positive because when these patients are vomiting you find that it takes sometimes to wear the hand gloves and I need to remove the vomits very fast.

Further interviews yielded further insight about the reasons why such occur. She said that although she knows full well the implications of not using protective devices especially

when handling body fluids, it is not that easy to put on gloves in emergency situations. The issue raised here relates to matching theory with practice. Circumstances such as the one described here hinder consistent use of protective devices though volunteers know the importance of it. They may prioritize the needs and wellbeing of the patient to their own wellbeing by putting themselves at risk.

A common theme that emerged from focus groups and also reiterated in in-depth interviews is the experience by volunteers of death and dying. Almost all the participants stated that they experienced some emotional and psychological problems as a result of caring for patients. Emotional problems start the first day volunteers visit patients. Many of the participants described their first visit to their patient's home as an emotionally charged experience:

In the beginning it affected me a lot though I didn't show it to the patient. I was crying profusely but still helped him in dressing up.

These emotional outbursts were attributed to initial shock at the physical state of the patients with full blown AIDS who are usually bedridden. The volunteers find it difficult to cope with the sight and the extent of degeneration of the AIDS patient. Although some of them were able to overcome this state of shock after a few visits to the patients, others took a longer time to adjust to their situations and yet some specifically ask to be excused from caring for patients with full blown AIDS¹⁴. In addition, volunteers are emotionally disturbed by watching the gradual deterioration in the condition of the symptomatic HIV/AIDS patients as well as those with full blown AIDS as they progress towards death. This experience was common among volunteers whose patients were just showing early symptoms of illness when they first visited them but whose health had gradually deteriorated over time. Watching their health deteriorate, they claimed, exposed their own incompetence in reversing the situation. The inability of volunteers to ease the pain and suffering of dying patients was attributed to their limited scope of practice and the fact that AIDS is incurable. The scope of practice of the volunteers is limited to basic nursing care. They are not allowed to administer either over the counter or prescription drugs¹⁵. Therefore when patients complain of pain, they can only refer to the clinics. They cannot do anything to alleviate their pain beyond basic nursing care and this is a usual source of emotional torture for them. They stated that although the patients and their families expect to see a remarkable turnaround in the patient's situation this is rarely the case especially with full blown AIDS patients:

Whenever we come they hope that we are going to bring solutions to all their problems only to find that our help is what we ourselves were told or trained to do.

¹⁴Sinosizo home based care project have been responsive to the emotional and psychological consequences of death and dying on volunteers and have granted volunteers who cannot cope the opportunity to work with walking well patients. Those who lose patients and/or family members frequently or are not coping with the burden of caring are also advised to take a break from volunteering.

¹⁵ Volunteers go through a short training period and are not adequately equipped to prescribe or administer drugs.

Even those who had been volunteering for some years still felt emotionally disturbed. Some felt that their effort as caregivers was not of any value since they could not reverse the deteriorating state of the patients. They stated that emotional effect on them is exacerbated when they bath the patients or help them to move from one place to another:

I used to bath her. I was feeling unhappy because sometimes when I am bathing her she used to cry. She was feeling pain and It used to hurt me. I also feel the pain and I used to cry as well.

A few of the volunteers who had sick relatives had to carry the emotional burden of caring for them as well as that of their other patients at the same time.

Participants reported that watching patients die is a horrific experience. Some described the experience:

I am afraid to see people dying in front of me. It is so painful watching patients die. I cannot help with anything because I cannot stand it when the soul is getting out of the body (dying).

Volunteers suffer emotional consequences as a result of losing their patients. One aspect of this is the fact that they cannot keep their minds off their dead patients. They recall their life and suffering before death and this evokes emotional outbursts.

It is very emotionally distressing. The consequence of which is the fact that I cannot sleep properly, cannot eat well sometimes because I will dream about these things especially when the person is in the last stage and are about to die.

Participants explained that the psychological trauma they suffer is exacerbated by the fact that they make an effort to have a friendly relationship with their patients and that they usually die when they are just getting to know they them well and ‘when their friendship is blossoming’.

This emotional state is rekindled when volunteers care for other patients in the final stage of the disease. It is sometimes so bad that some of them tend to avoid taking on patients who have full blown AIDS because of the fear of losing them the way they lost the previous ones.

Many of the volunteers reported having feelings of guilt when they lose their patients. This is compounded in many cases by community attitudes (discussed later).

I become very worried when the patient passes away because I even feel guilty that maybe I did not do enough.

We take responsibility as volunteers that maybe we did not do enough for the person, maybe if we did this person wouldn't have died.

A participant could not find words to express her pains as a result of losing a patient on whom she had done expended so much effort and time.

The other aspect is dealing with the emotional effects of watching the family suffer. Many of the HIV/AIDS affected families cannot afford the basic necessities of life such as food, money for transport and school fees. This according to them is made worse when the patient dies and leaves needy children and family behind. It is ironic that whereas volunteers themselves grief and suffer some psychological and emotional effects when they lose their patients, they still have to go to their patients families to offer support and bereavement counselling. In sum, some of them feel depressed and many of the participants lamented that their patients 'put a lot of their hopes in them'.

In view of the psychological consequences of providing care to PLWHAs, participants were asked to describe the steps they usually take to deal with the emotional stress that their routine work presents. Many of them said they told their colleagues about their emotional problems and that they were usually advised to endeavour to not dwell too much on it. They also indicated that they do have some volunteer supporters who supports and assists them to go through the grieving process. Some however stated that they usually go to their pastors to pray for them. Others said that just going to the Church to sing and dance will suffice.

Risky behaviours of primary caregivers

One of the challenges that volunteers face is convincing primary caregivers of PLWHAs to use protective devices while caring for their kin. A participant described the case of a sibling of a PLWHA who upon being discharged from the hospital said I am going to take good care of my sister and I do not need gloves'. She continued:

There are parents who will say they love their children and they will touch them, wash them and do everything even if you teach them about the use of gloves, they do not believe in gloves.

They believed that some primary caregivers get infected with HIV by refusing to use gloves while caring and cited the case of 'a woman who died of HIV/AIDS because she used to care for her daughter with her hands without using gloves'. We sought to know whether there is a cultural reason why some parents refuse to use gloves while caring for their patients but were told by focus group participants that these people believe that it is not proper to touch their loved ones using gloves since it would depict them as uncaring. They also cite instances where primary caregivers asserted that do not need gloves to take good care of their relatives. Similar notions on the use of protective devices for caring were expressed by family caregivers in a previous study in KwaZuluNatal (Akintola, 2004b). There seem to an underlying belief that gloves put a barrier between one and their loved ones and thus signify a lack of love for the sick. Although volunteers explained to primary caregivers the value of using protective devices while caring some caregivers still would not bulge because according to the volunteers, 'they are stubborn'. This finding should be seen in the light of the stigma and discrimination that accompanies

the disease already discussed previously. The high prevalence of stigma and discrimination against people living with HIV/AIDS has sensitised some to the point that they put themselves at risk in order to show that they are not discriminating against their patients. Volunteers in the study conducted by Akintola (2004b) had to sometimes lie to patients about the reason why they used gloves, stating that it is mainly to prevent the patients from being infected by germs. They however rarely revealed to them that it also protects the caregivers from being infected by the patient.

Socio-economic issues

The socio-economic situation in which volunteers provide care was explored as well. Volunteers stated that their family life and social activities are usually affected indicating that family duties and responsibilities are sometimes left unattended because of the demands of the caring job. Some however stated that they work out their schedule in such a way as not to disrupt their volunteering duties. Some indicated that they wake up early in the morning to do their house chores before going out to their patients. Most of the volunteers' patients are living in poverty and volunteers are constantly confronted with the practical reality of having to care for patients who do not have food to eat. More difficult is monitoring drug adherence for HIV/AIDS/TB patients who do not have any food to eat. Many of them complain bitterly to the volunteers expecting them to do something about their situation:

‘You are visiting my family and you see that we do not have food here you can see that my children are without food’.

Volunteers often are helpless and occasionally have to spend their money in order to assist patients who are in dire need:

Most of these people are living in poverty and you find that as a volunteer I am the one who has to dig into my pocket and yet I am not getting paid

This financial assistance is usually channelled towards feeding patients or paying for transport to the clinics. And in cases where volunteers cannot do not have money they solicit help from the patients' neighbours or other community members. It should be noted that volunteers are not paid and many as noted previously, do not have a source of income.

Volunteers indicated that they are usually handicapped and unhappy because of their financial situation:

Even we volunteers are living in poverty and yet we are doing our work with huge commitment. We cannot afford to feed our families or send our children to school because we are not being paid

Another major challenge relates to the social aspect of patient's lives. Volunteers assist patients with preparing of documents for social grants but some patients do not have these documents and some are too sick to find them. Some die without leaving any of

their own or children's documents that could be used in applying for grants for their families when they die. This hinders the process of securing social grants and therefore the alleviating poverty in the affected families.

Whereas volunteers reported that they had a cordial relationship with the local clinic staff in Groutville and Etete, the contrary was the case in Siyanda. One of the problems confronting the volunteers in this community is the lack of a clinic to which they can refer their patients. Being an informal settlement, they do not have any government facility present in the community. They reported having to make use of the clinics in neighbouring communities of Kwamashu and Newlands East. Even so, clinic officials sometimes deny them the use of the clinics referring them back to other clinics. Sometimes they have to stand in queues for hours when they take bedridden patients to the clinics. The distance between the clinics and community also present a problem and volunteers sometimes have to transport bedridden patients to the clinics on their own backs or in wheel barrows whenever they are unable to reach ambulances.

Volunteer's expressed needs

The need for personal development was a common issue raised by the volunteers. Participants voiced the need to be assisted by government to improve their situation. One of the areas in which they believe assistance should be targeted is their education. Many of them as noted have low-level of education and some could just not afford to further their education although a few indicated that they had passed their matriculation examinations. Those who had failed indicated that they could not afford to pay for a retake and they believed that assistance to further their education would enhance their effectiveness and efficiency on the job. They noted that their poor understanding of English impacts negatively on their work particularly in communicating with people. This is especially so when they have to communicate with doctors in the clinics or hospital, stating that the nurses who interpret for them sometimes misinterpret.

The level of resistance that volunteers experience from some community members has led them to soliciting support from the government to help by working to make sure that they are better recognised in the community. This they believe would raise the level of awareness in the community about volunteers and also facilitate their work.

Volunteers stated that although they have contributed to the development of the communities by assisting families to care for years, there was no evidence to show that anybody in government appreciates their work. All the volunteers alluded to the fact that they do not have money to look after themselves or to buy basic needs yet as one said 'we are so helpful in the community and have been volunteering for years'. All the volunteers expressed the wish to be paid some stipend not so much for their services but as a token of appreciation and for them to take care of their basic needs and feed their families. They however claimed that it was not enough to take care of their needs.

Many lamented their financial state and a few bemoaned their lack of income from the work they do as volunteers:

I have been depending most on my mother and now I am old enough to stand on my own. My mother is tired of me, she has played her part and now I am supposed to be supporting her.

Although many of the volunteers said they loved to keep volunteering on a part time basis even if they found a paying job, a handful mentioned that they would quit if they get a paying job saying that it would be difficult to combine both because of the demanding nature of caregiving for PLWHAs.

Attrition among volunteers is high and is posing a threat to the volunteer programme. The programme officer indicated that the programme lost 48% of their volunteers last in 2004 alone. Most of the volunteers left for paid jobs such as community health workers, working with drop in centres and some even work in areas that are not related to health or caregiving. Some of the volunteers who are HIV positive quit because of illness while some quit because they are fed up of working without being paid and yet others quit because of personal problems.

The rewards of volunteering

Schwartz and Gidron (2002) notes that caregiving can be a rewarding experience giving meaning and heightening the caregiver's sense of self-worth. Participants described their positive experiences with volunteering. They appreciated the knowledge and skills that they learnt from the training received mentioning each aspect of the training such as knowledge and skills on HIV/AIDS prevention, basic nursing care, DOT (Direct Observation Treatment). They also learnt how to talk to patients and their families and to counsel the primary caregivers on how to care for their patients. One said 'I did not know anything about it (HIV/AIDS prevention and care) but now I know'. This knowledge has also been passed on to others as well. A few also stated that the training they received places them a step above other community members who were not trained. Additionally, volunteers claimed that the practical experience of learning from the problems of their patients and their families makes them grow and teaches them patience, and problem solving skills. They felt accomplished and happy that that they could help their community to live better lives.

One of the volunteers cited the fact that she is now well known by members of her community who are appreciative of her efforts and that this implies that she is 'making a difference in people's lives'. A common source of joy for many, is seeing their patients getting better particularly patients who are in the early stages of symptomatic HIV/AIDS and those who have TB.

CONCLUSIONS

This study brings to the fore the activities of volunteers and the challenges of volunteering within the context of a particular model of home based care. Although many of them are unemployed and themselves living in poverty, they are generally driven by magnanimity and the will to make the lives of their patients better. They carry out their work with a sense of commitment and dedication earnestly seeking to end the misery of community members and in the process, often confronting other problems that complicate their lives and that of their families. Indeed volunteers play a major role in mitigating the burden of care for PLWHAs and constitute the backbone of this model of home based care operated by Sinosizo. They are thus an invaluable resource to affected households, communities as well as the health care system.

Nonetheless, there appears to be a pervasive erroneous notion among the affected families that volunteers are paid to care for them. Also to be noted are the deliberate or perhaps desperate attempts by frustrated family members of the sick people to shirk their responsibilities. At the same time, government's support is lacking. Thus, this raises questions around who should take the responsibility of caring for people living with HIV/AIDS and what the government's role should be.

Clearly, a substantial part of home-based care costs are borne by volunteer caregivers who are largely poor, infected and affected women thus exacerbating their burden. Although volunteers identified logistical as well as physical health problems, the major problems seem to be their own poverty and that of the affected families as well as mental stress caused by the performance of caregiving activities. There is therefore a great need for mental health services as well as material and financial support for volunteers and affected families. These two issues largely explain the high attrition rates reported by the home-based care programme. The former assertion is supported by information on motivations of volunteers which provide useful insight into why volunteers offer to care without being paid. It is argued that government needs to urgently prioritize these two issues in order to stem attrition of volunteers. Of critical importance is the need for psychosocial support services to be integrated into primary health care programmes.

While acknowledging that this study does not provide information on the magnitude of problems encountered by volunteers, the narratives highlight the daily painful realities of the lives and work of volunteers and by extension the challenges of the home-based care models that make use of volunteers. It is suggested that a comprehensive assessment of volunteer programmes in the country be carried out in order to understand better the nature and extent of problems. This will be useful in the development of policies on home-based care in the country.

The findings of this study also raise a number of research questions:

- What are the experiences of paid 'volunteer' caregivers? Are they different from those of unpaid volunteer caregivers?
- To what extent does the primary health care programme integrate home-based care programmes and how has these affected volunteers?

- What are the functions of volunteer caregiver support groups and how do they meet the psycho-social support needs of volunteers.
- What are the experiences of volunteers who quit the programme and why did they quit?

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