

*Hlengiwe Hlophe*

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## Home-based care as an indispensable extension of professional care in ART — a plea for recognition and support

The Centre for Health Systems Research & Development is currently conducting a longitudinal study to assess the implementation of public sector anti-retroviral treatment (ART) in the Free State. Home-based care (HBC) is central in achieving good patient follow up, continuity of care and patient adherence to treatment. This paper considers the role of HBC in strengthening the ART programme and identifies barriers to effective HBC. To this end, group interviews were conducted with HBCs in the Free State. Problems in respect of training, resources, stipends, support, supervision and management were revealed. Amongst HBCs and primary health care nurses confusion occurred about HBCs' roles and duties. It is recommended that gaps in policy implementation in respect of HBC should be addressed and that HBCs' roles should be clarified.

Tlhokomelo ya lapeng jwalo ka ntho kapa katoloso ya bohlokwa ya tlhokomelo ya boemo Bo phahameng tabeng ya sethethefatsi sa ART — e leng kopo bakeng sa ho amohelwa le ho tshehetswa.

Setsi sa Mekgwa ya Dipatlisiso le Ntshetsopele sa Bophelo bo Botle hajwale se etsa thuto ya ho botsa dipotso ka mora nako e itseng ho fihlella ho kenywa tshebetsong phekolo ya sethethefatsi sa ART ya thibelo setjhabeng ho la Freistata. Tlhokomelo ena ya malapeng keya bohlokwa ho fihlella hore kalafo ya mokudi e salwe morao, tlhokomelo ya mokudi ho tswela pele e hokahane le phekolo ena. Pampiri ena e tadima mosebetsi wa Tlhokomelo Ya malapeng ho matlafatsa le ho tiisa lenaneho la sethethefatsi sa ART le ho hlwaya kapa ho bontsha ditshitiso hore Tlhokomelo Ya Malapeng e phethahale. Ho fihlella mona, ho botswa ha dihlopha ho ile ha etswa le ba Tlhokomelo Ya Malapeng ho la Freistata. Ho ile ha hlahiswa mathata mabapi le thupelo, mehlodi, meputso, tshehetso, taelo le tsamaiso. Hara baoki ba Tlhokomelo Ya Malapeng le ba tlhokomelo ya mantlha ya tsa bophelo bo botle ho hlahile pherekano e kgolo ka mesebetsi le karolo tse etswang ke ba Tlhokomelo Ya Malapeng. Ho kgothaletswa hore dikgaello le ho kenngweng ha leano mabapi le Tlhokomelo Ya Malapeng ho lokela ho etswa le hore mesebetsi ya ba Tlhokomelo Ya Malapeng e hlakiswe.

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**H**IV/AIDS is one of the leading causes of death in many sub-Saharan African countries including South Africa.<sup>1</sup> Evidently, it affects all sectors of society; however, the most severe effects occur at household and community level (Akintola 2005:1). 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 the informal caregivers carry a considerable part of the burden.<sup>2</sup> In the USA, for example, caregivers perform a variety of roles that help people adhere to treatment regimens, avoid unnecessary hospital admissions and maintain quality of life. They also play an important role in identifying and managing symptoms and side-effects, yet most are thrust into these roles with little or no training; while HBCs may also be required to perform multiple and sometimes conflicting roles (cf O'Neill *et al* 2003).

The South African government has identified HBC as a key priority area for development and therefore released *National Guidelines on Home-Based Care & Community-Based Care*, which is intended to serve as a guide for the promotion of HBC in the country (NDoH 2001). HBC was developed as a strategy to limit the demands on the formal health system by providing care that is close to people's homes and their families. Hence, HBC links and complements existing health services, and promotes a holistic approach to care (Friedman 2005: 177; Kenyon *et al* 2001: 175). In most cases the HBC strategy is considered to be the only solution for sick people and their families, given the inability of health care facilities to accommodate critically ill and specifically AIDS patients.<sup>3</sup>

- 1 I am grateful to my colleagues, Prof Helen Schneider and Dr Christo Heunis for their comments on an earlier draft of this article. The views expressed in this article are, however, my own. Note: Citations of statements or remarks made during meetings of the provincial Task Team or in other official meetings related to the ART programme are anonymously referred to as FSDoH official, FSDoH clinician provincial Task Team meeting with the date of statement or remark.
- 2 According to the National Guidelines on Home-based care and Community-based care, informal caregivers include volunteers, caregivers, community health workers and families (National Department of Health 2001: 8). Cf Akintola 2005: 1; Barnett & Whiteside 2002: 193; Campbell & Foulis 2004: 2; Russell & Schneider 2000a; UNAIDS 2001.
- 3 Cf Campbell & Foulis 2004; Campbell *et al* 2005; Johnson *et al* 2004; Lindsey *et al* 2003; Ndaba-Mbata & Seloilwe 2000.

The WHO defines home-based care as any form of care given to ill people in their homes, including physical, psychosocial, palliative and spiritual activities (NDoH 2001: 1; NDoH & NDoSD 2003).<sup>4</sup> This is done to promote, restore and maintain a person's optimum level of comfort, functioning and health, including care towards a dignified death (Campbell 2004: 22). HBC programmes play a significant role in providing care and support for people with HIV/AIDS and other chronic diseases and in developing the community. However, the programme is faced with challenges with respect to the provision of care and support. Some of the challenges include inadequate support structures for HBCs; insufficient empowerment of HBCs regarding care and resources, as well as economic constraints and exhaustive care needs. Russell & Schneider (2000a: 1) argue that HBC initiatives urgently need support at every level of society. With reference to HIV/AIDS, HBC services were envisaged to provide not only care, but quality and effective care to people living with HIV/AIDS. However, HBC resources for people living with HIV/AIDS have been limited.

This paper considers the role of HBC in strengthening the ART programme and aims to identify barriers to effective HBC with specific reference to the ART programme. Moreover, the study aims at informing health policy-makers and managers of the gaps in the HIV/AIDS/ART policy implementation. It is widely believed that HBCs play a vital role in the HIV/AIDS and ART programmes. However, there are barriers to HBC that need to be addressed to ensure effective care and support for patients in the ART programme, as well as for their families. To this end, the paper discusses the research methodology, the rationale for HBC; investigates literature considerations and South African policy on HIV/AIDS and HBC, and presents results and discussion. Lastly, a conclusion and recommendations are made.

## 1. Methodology

The contribution flows from a larger study currently conducted by the Centre for Health Systems Research & Development (CHSR&D), namely *Public sector ART: documenting, monitoring, evaluating and facilitating the*

<sup>4</sup> For the purposes of the study, HBCs include volunteers working as HBCs, DOT supporters and ARV treatment supporters.

*implementation of the national treatment plan in the Free State.* The current contribution is exploratory and descriptive, using qualitative research methods to provide in-depth data about HBCs' experiences and perceptions of the ART programme.<sup>5</sup> Purposive sampling was used to select respondents. The study was conducted among volunteer HBCs working at ART assessment sites in all districts of the Free State.<sup>6</sup> The study involved 201 HBCs from 16 ART assessment sites. Group interviews were conducted with HBCs in each assessment site (16 group interviews). Participants were given a verbal guarantee that any information offered would be kept anonymous and confidential, and that their participation in the study was voluntary. A verbal consent to be interviewed, including the use of a tape recorder, was obtained from participants.

A group interview schedule covering topics such as the type of care provided, problems experienced, the availability of support and resources, as well as the sufficiency of training and skills, was developed and used. Participants were requested to complete a participants' list (containing information on gender, age, etc). Questions were in English, however when presented in participant's languages, participants were allowed to speak in their own language since facilitators (one of them responsible for a tape recorder and taking notes, and the other for conducting interviews) were fluent in the languages spoken. Local languages included IsiZulu, IsiXhosa, Sesotho, and Afrikaans. Tape-recorded data were transcribed *verbatim* and translated into English. Group interviews were supplemented by a desktop literature review of documentation and policy regarding HIV/AIDS/ART and HBC.

Descriptive counting is used to present the findings. Values provided serve as a rough guide as to the frequency of views, experiences and needs as voiced by respondents (Morgan 1997: 61). Findings are as far as possible supported by direct quotations and in an attempt to quantify the (qualitative) data gathered, the "frequency" values/indicators are used. It should however, be noted that descriptive counting repre-

5 The focus of this paper may be different if the opinions of other stakeholders are presented. However, the aim of this contribution is simply to present the views, perceptions and experience of HBCs — a valid scientific approach. Approaching the topic from different perspectives falls outside the scope of this contribution.

6 ART assessment sites are defined as referring primary health care facilities — clinics or community health centres.

sents the total number of group interviews, and not the total number of participants.

HBCs were mainly females ( $n=189$ ), with fewer males ( $n=12$ ). The ages of HBCs ranged between 25 and 70. Only 61 (30%) HBCs were receiving the stipend, regardless of the qualification criteria for the stipend. Most of HBCs had HIV-positive, TB and bed-ridden patients under their care; however, the majority was not cognisant of the nature of their patients' illness, due to confidentiality issues.

## 2. Rationale for HBC

Due to HIV/AIDS epidemic and an increase in non-communicable diseases, it is necessary to consider how best to provide care for people with diseases and their families. HIV/AIDS has become South Africa's most prominent health problem with some hospitals reporting that AIDS patients occupy a third of their beds (Kenyon *et al* 2001: 175). Moreover, as the number of people falling ill increases, many will not be able to stay in hospitals, hospices or other institutions of care. The inadequate number of medical, nursing and allied health professionals in the public sector, a shortage of hospital beds, a lack of resources for treatment and drugs, and the cost of institutional care will render this impossible.

HBC in South Africa, therefore, sets out to provide backup for people who need extended care and patients discharged early from the hospital. HBC is not cheap, but provides an ideal solution for commonly occurring diseases that can be effectively managed at home.<sup>7</sup> Ageways (2001: 4) and Campbell *et al* (2005) also argue that HBCs have become a major source of help for people living with HIV/AIDS, they provide basic HIV/AIDS care and education, general HBC and support for people with HIV/AIDS. According to Cruz (1997), HBCs provide a more affordable first-level contact within the PHC system than other health providers. Akintola (2004: 23) and Lindsey *et al* (2003: 499) are of the opinion that caregivers need psychosocial support, because their work is exceptionally stressful on a physical, psychological, social and economic level.

7 Cf Cruz 1997; Friedman 2002: 162F; Russell & Schneider 2000a; WHO 2004.

### 3. Literature considerations

The rollout of the ART programme in South Africa has provided first glimmerings of hope for people living with HIV/AIDS. Besides providing hope to individual sufferers, the availability of ARV treatment is widely regarded as a pillar for effective HIV/AIDS management at all levels. However, the rollout process is associated with risks and fears, as well as with hopes and opportunities. One of the fears is related to the risks regarding the development of drug resistance due to poor adherence to the treatment programme (Campbell *et al* 2005). Consequently, the ART programme in the public sector evidently relies heavily relying upon the support of communities to ensure effective rollout.

The rollout of the ART programme has introduced transformed roles and functions for HBCs. Traditionally, the role of HBCs has been the provision of palliative care to patients; however, this is considered to change due to the ART programme. The ART programme prolongs the lives of those who have reached the stage of full-blown AIDS. Thus, the anticipated role of HBCs includes providing treatment and support to healthy people in the ART programme; therefore, the programme's demands pose new responsibilities and skills for HBCs. The role of HBCs is destined to become even more crucial in carrying the ART programme forward. Such expansion of the CHW system calls for an enlargement of the pool and a strengthening of capacity and skills.<sup>8</sup>

HBC is a useful tool to assess and support patient adherence to ARV treatment and other therapies, including locating and reaching out to patients who miss scheduled appointments, promoting continuity of care and adherence with ARV regimens (Campbell *et al* 2005; NDoH 2003: 58). Furthermore, HBCs do not only provide support and care to patients in the ART programme, but could assist in meeting human resource needs of the ART programme, especially in rural and neglected areas. CHWs are slowly taking on some of the functions and roles of professional nurses.<sup>9</sup> The reasons behind the shift in roles are envisaged to deal with increased levels of migration among health care providers, an increased workload among health care providers due to the demands

8 Provincial Task Team meeting 8 November 2003.

9 CHWs include HBCs (DOT supporters and ARV treatment supporters) and lay counsellors.

of the ART programme, the loss of health workers to HIV/AIDS and the expansion of services to deal with HIV/AIDS and illnesses related to the disease (cf Dovlo 2004).

The use of substitute health workers as referred to by Dovlo (2004) could also prove helpful as a mechanism of retention to counter the effect of migration by health care providers.<sup>10</sup> In their study, Bekker *et al* (2003) also found that the incorporation of CHWs into the ART programme increased community involvement and utilised valuable and untapped resources. However, there is concern about the lack of support for and supervision of HBCs, which could hamper the quality of care and support rendered (Friedman 2002: 174).

The indispensable role of HBCs in the success of the ART programme has been recognised not only in South Africa, but throughout the world. Walker *et al* 2003 argue that in Uganda, HBCs have been found feasible in extending antiretroviral treatment to AIDS patients in resource-poor settings. Moreover, a method known as directly observed highly active antiretroviral therapy has been adopted in Haiti, where HBCs visit people receiving ARV drugs at home on a daily basis. HBCs are expected to deliver drugs, observe the person's daily doses, provide support and respond to family concerns (cf Walton *et al* 2004). Studies conducted in Haiti found that adherence to treatment improved due to the availability of HBCs (cf Grubb *et al* 2003).

#### 4. The South African policy

Russell & Schneider (2000b: 328) argue that the burden of HIV care has fallen upon households and communities and, as a result, HBC has become a national policy priority in South Africa. The *Operational Plan for Comprehensive HIV and AIDS Care Management and Treatment for South Africa*, launched in November 2003, emphasises the provision of comprehensive care and treatment for people living with HIV/AIDS and the need to strengthen the national health system in South Africa. According to the *Comprehensive Plan* (NDoH 2003: 59), HBCs have a role in disseminating prevention messages. HBC services can also make a consi-

10 Substitute health worker cadres take on some of the functions and roles normally reserved for internationally recognised health professionals, such as pharmacists and nurses, but they usually receive shorter training and possess lower qualifications.

derable contribution to minimise fear and discrimination, providing and reinforcing accurate information to address stigma surrounding HIV infection. Together, these mechanisms help to ensure that persons living with HIV receive ongoing information, care and support to minimise the risk of transmitting the virus to others and curb the progression of the disease.

The *Comprehensive Plan* (NDoH (2003: 28) further states that

the available care and support services such as transportation, HBC, hospice services etc, often provided by Non Governmental Organisations (NGOs) and Community Based Organisations (CBOs), will assist in keeping people in care and encourage their adherence to treatment.

There is no doubt that the link between the PHC facility and HBC services is central to achieving good patient follow-up and continuity of care. In recognising the role of HBCs in the ART programme, both the, *Comprehensive Plan* and the *National antiretroviral treatment guidelines* (NDoH 2004) strongly accentuate the training of HBCs as ARV treatment supporters, to ensure patients' adherence to treatment. In addition, *The Primary Health Care Package for South Africa* (NDoH 2000) also emphasised the training of HBCs by NGOs, local clinics or visiting health teams to ensure the rendering of effective HBC services.

In 2001, the Free State Department of Health (FSDoH) and NGOs including CANSA and Bloemfontein Hospice worked closely together to implement a province-wide system for HBC of people in need of care. This included people living with HIV/AIDS, cancer and other serious conditions. The programme aimed at improving the quality of life for people cared for at home by volunteer carers (Herbst 2005: 8). The Free State community-/home-based care (CHBC) model is headed by NGOs in collaboration with other partners that maintain a good working relationship with structures driving the initiative. The intervention, firstly, comprised the training, supervising, and equipping of volunteers; secondly, standardising methods and quality of care, and thirdly, co-ordinating government and NGO health and welfare services.

The FSDoH released its *Free State NGOs Policy* in July 2004, which acknowledges the crucial role played by NGOs in the implementation of health programmes at grassroots level and that, for this reason, a health partnership between local NGOs and the Department is essen-

tial. The *NGOs Policy* (FSDoH 2004) thus outlines the relationship between the Health Department and various NGOs working with the department, as well as the standard operating procedures aimed at securing sound and effective resource distribution for the provision of health care and services within the province. The specific services to be rendered by NGOs in the province include providing care, counselling, support, education and training or awareness programmes, and the provision of other health-related services to the community.

The vision of the Free State province in respect of HBC is the provision of a holistic, effective, sustainable and integrated CHBC programme. The corporate and strategic goals of the FSDoH is to develop and maintain integrated HBC and step-down facilities; to develop and implement a policy for cadres of community workers who will assist with services such as HBC, step-down facilities and voluntary confidential counselling and testing (VCCT); to build capacity at all levels of care and to strengthen existing CHBC programmes by introducing food security programmes for patients and their families; as well as monitoring and evaluation, including the development of CHBC monitoring tools (FSDoH 2003). *The Free State Policy on Voluntary Work* (FSDoH 2002) clearly states that a co-ordinator responsible for managing and controlling the volunteer work needs to be identified and appointed.

Furthermore, the policy outlines that the scope of practice should clearly define the functions, and the level of performance required must be clearly stipulated to all voluntary workers. The *NGOs policy* states that, in order for volunteers to qualify for stipends, NGOs must ensure that the volunteer has signed a memorandum of agreement with the Department of Health; volunteers for HBC have completed national standardised training; the volunteer is linked to a local or community health care centre and should report to the supervising clinic personnel weekly or monthly, depending on the rules of the clinic; the volunteer has at least three very ill patients whom she/he has been taking care of for the month in question, and the volunteer has completed claim forms with a clear summary of the duties performed and the number of patients cared for. Even though the policy stipulates conditions for the payment of a stipend to volunteer HBCs, it is regrettable that this does not happen in practice. It therefore necessitates the development of strategies to ensure effective policy implementation.

## 5. Results

This section identifies the themes that emerged from the group interviews with HBCs. These exemplify key barriers to effective HBC. Issues related to HBC rendering are presented. They include the role of HBCs and point out inadequate training; management, support and supervision; remuneration and communication breakdown; shortcomings and gaps, and expectations and experiences of HBCs.

### 5.1 Unclarified roles and inadequate training

HBCs carry out a wide range of activities, assisting people in need of care and support in their communities. However, it became apparent that there is much confusion regarding the duties and responsibilities of HBCs. When describing their roles (Table 1), HBCs cited that some of the tasks allocated to them do not fall within their scope of practice (non-HBC roles). Some of these tasks are believed to have been imposed on them by professionals from individual PHC facilities. Participants also mentioned additional roles emanating from the ART programme. HBC roles on the other hand, were believed to be legitimate roles of HBCs. Participants were cognisant of such roles, and believed that these roles fall within their scope of work. However, they were unclear as to their exact role, since no written documentation pertaining to their role was given (GI=16). According to HBCs, confusion regarding the roles and responsibilities of HBCs existed not only among HBCs, but among the professional nurses and the communities as well. The issue of unclarified roles between HBC and professional nurses has resulted in some tension between the two groups:

Some of the nurses are not supportive; they treat us as if we are nothing, they tell us that we are lazy and we do not clean the clinic yard. We are HBCs, not garden boys. What exactly are we supposed to be doing, because nurses do not even know what our roles are.

While HBCs are supposed to relieve families of the burden of care by teaching the family members skills and knowledge on various issues relating to the care and support for an ill member, the practicalities compel them to go beyond this line of duty. In part this is because communities and families are misinformed about the role and responsibilities of HBCs. Participants mentioned that families believe that HBCs are there to care for and support the family in addition to caring for

an ill person. As a result, they have shifted their responsibilities of providing care and support to HBCs. This has created confusion and an unpleasant situation among HBCs and involved entire families. This situation calls for urgent attention, since it is without any doubt affecting efficient HBC service rendering negatively. Moreover, participants also talked of feeling overwhelmed by all the responsibilities that have been thrust upon them. It is essential that the role of HBCs be made known to all concerned, to avoid confusion and conflict:

It worries me that our community and patients' families have left everything to us. They do not want to help; the patient always has to wait for me before having the linen changed and food to eat. The family members just sit there; watch me while struggling to bath, and feed the patient. They do not help us; we have to do all the work on our own. We are there to help the family not to take over their responsibilities.

An important issue pervading much of the data was insufficient training among HBCs. HBCs believed that they have insufficient training and lack necessary knowledge and skills to perform their duties (GI=14). One of the areas that participants believed should be targeted, was their education and training. The majority of the participants (GI=15) do not have training in the ART programme, notwithstanding having to care for patients on ART. The ART training was the most needed training among the participants, since the majority was ARV treatment supporters. This training is deemed essential in order to ensure a patient's adherence to treatment and to identify possible symptoms of side-effects.

Table1: Roles and responsibilities of HBCs

HBC roles	Non-HBC roles	New roles linked to ART
Provide basic nursing care eg bathing and dressing patients and washing clothes and bed sheets	Assist in the reception area in facilities	Assist patients in taking medication
Educate patients and families	Provide own food to patients	Provide support to patients
Fetch drugs from the clinics (TB treatment)	Do gardening at the PHC facilities	Trace patients (treatment defaulters)
Link the community with resources and services	Arrange transport for patients	
Feed patients and give medication	Clean the clinic yard	
Assist in step-down facilities		
Provide awareness and health promotion		
Referrals to various departments and centres		
Clean the home		
Provide basic counselling and information to patients		
Offer physical rehabilitation to patients		

Some of the HBCs never received training on HBC, while some only received training on Directly Observed Therapy, Short-course (DOTS). Some of the DOT supporters, on the other hand, have not been trained to provide HBC and support (including bathing and dressing wounds) to their bed-ridden patients. HBCs mostly care for HIV/AIDS patients and reported that they lack basic training on counselling. Such training is considered essential for volunteers to be able to provide effective counselling, especially to HIV/AIDS patients and their families:

Some of our patients need counselling and we cannot help them, because we do not know how to counsel a person. We do not have training on counselling. This makes things difficult for us. They talk to us because they trust us, we cannot refer them to someone they do not know for counselling, because they do not want to talk about their problems just to anybody else.

We were only trained as DOT supporters. We provide home care to patients but we never received training on HBC. Some of us never received any training in our lives, but we are caregivers. We do not even know what to do and what not to do.

## 5.2 Management, support and supervision — a looming unhappiness

The attitude of the professional nurses and patients' families was explored in order to understand the sources, and nature of support, and how these influence volunteer HBCs' performance of their tasks. HBCs stated that they received insufficient support from the professional nurses at the facilities (GI=13). The majority of participants felt that professional nurses do not appreciate their work. Even though participants were generally satisfied with their relationship with professional nurses, the majority of participants pleaded for any form of support by the professional nurses:

It feels so painful when we are told that we should not forget that we are volunteers. They try to satisfy the government and they are satisfied with the progress that patients make but forget that volunteers are the ones who make all this possible. Nurses never visit patients, we do that, but at the end of the day, all the credit goes to the nurses. We work under pressure, the Department of Health does not value us, we are stressed. It worries me to see that our government only wants the job to be done. Nobody cares about us.

Very few professional nurses support us at the clinic. I went to the nurse and told her that the patient came to me with some medication and asked me to help. The nurse yelled at me and told me that we are HBCs; we do not know anything about ARV drugs. I told her, because I wanted clarity, and instead she shouted at me. I would not say we receive support, because they do not involve us in the ARV programme; we need to be informed and be educated in order for us to be able to help our patients. However, they involve us in some things, like when we have to do awareness programmes with them.

Contrary to what the majority reported, some respondents (GI=3) clarified that they were supported by the professional nurses at their specific PHC facilities. Support provided by professional nurses included emotional support to volunteers, as well as support in terms of dealing with difficult patients, especially treatment defaulters:

The support we receive is good. If we have patients who do not want to take treatment and very poor patients, we report to staff nurses and they go with us to the patients to see what is going on, and what they can do to help. They support us especially when we are depressed

by the situation that we are working in; they are always motivating and encouraging us.

Participants were dissatisfied with the services and lack of recognition from the Department of Health (GI=11). Such statements were supported by the fact that volunteers have stopped doing some of the things that benefited patients (for example gardening and providing vegetables to patients) after realising that their work goes unnoticed. Moreover, considerable friction and discomfort was noted regarding the promises made by the Department of Health. The promises included increment in terms of volunteer stipends to R1000 from the current R500. Participants displayed a sense of discouragement and loss of interest due to a lack of recognition from the Department of Health. Participants believed that, even though they have made considerable contributions in their communities for years, there was no evidence to show that anybody in the government sector appreciates their work.

Communities were reported to have had a positive attitude towards HBCs and their work. However, some families did not accept HBCs. This was evident in cases where family members would hide an ill family member from having contact with HBCs, alleging that the patient was unavailable.

Some families do not want to work hand in hand with us; they hide patients from us. Sometimes I visit the patient and the family would tell me that no one is ill in the household. Some families would tell me that the person I'm looking is not available while the person is actually in the house.

In most cases, family members accepted HBCs, without offering support, however. Many of the families are under the impression that HBCs are paid by government to care and support the whole family as well as an ill family member. This was the case in situations where the family would refuse to assist an ill family member, claiming that it is the HBCs' responsibility to do so (GI=9). Consequently, HBCs are called in even at night and during weekends to attend to an ill person or to organise transport for the person to go to the hospital. This confusion about the responsibilities of HBCs has been a general source of conflict between volunteers and affected families:

The problem is that families do not want to take responsibility for an ill family member. They are too much dependent on us; they even

call us at night, or during the weekend to attend to an ill person. I sometimes bath a patient on Friday and on my return on Monday, I usually find him still with same clothes as I dressed him on Friday. The family does not even bath a patient. We try to teach the family what to do when we are not around but they never do anything. They believe that it is our responsibility to care for the family as a whole. I think the community need to be educated about home-based care; they should know that we are there to assist families in caring for ill persons.

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 (GI=4) This included neglecting them, locking them up, putting them in separate rooms, and refusing to share with patients. The attitude of these families suggests a low level of knowledge about HIV/AIDS transmission:

Our patients are treated differently after disclosing their HIV status to the families. Families usually develop negative attitude towards them. I have a patient experiencing this problem. The family kicked him out of the house after disclosing his status. They [the family] built him a small room next to the house. He has his own things, and the family does not want to share anything with him, he cooks his own food and uses his own plates and spoons. The family does not want anything to do with him.

Confusion concerning the supervising institution or organisation surfaced during interviews. The majority of participants was under the supervision of various NGOs, whereas some reported being under the supervision of the Department of Health. The majority of participants reported being supervised by one of the clinic nurses, however, others did not have a supervisor at the clinic level (GI=2). HBCs felt that district HBC co-ordinators were actually not performing their duties because they have never consulted with HBCs (GI=4).

### 5.3 Remuneration and communication breakdown

Uncertainty regarding the institution paying volunteer stipends was noted, as some of the participants reported being paid by the Department of Health, while others are paid by NGOs. Some of the participants were not knowledgeable as to which organisation pays out their stipends. One of the important factors mentioned to be discouraging volunteers, was the fact that monthly stipends are often delayed and not paid out as stipulated by the Department of Health:

We are paid by CANSA. We submit monthly reports and our claim forms monthly to the organisation. There is no support because we tell them our problems, they promise they will do something, but that never happens. Secondly, they do not pay us monthly, as they are required. They pay us anytime when they feel like, and sometimes they do not pay us at all.

Volunteers submit monthly claim forms and reports to the NGOs via the clinic manager in order to receive remuneration. However, it became evident that the allocation of stipends is not handled in a uniform manner, given the fact that some HBCs communicated that they were not paid despite forwarding all the necessary documents. According to participants (GI=13), there was no contact between HBCs and the responsible NGOs. Participants were of the opinion that it is almost impossible to lodge a complaint or report problems about their work situations. HBCs felt that NGOs should have meetings with HBCs at least once a month, and they felt that they have a right to know the people from NGOs:

It is very strange; they never worry about getting to know us. We submit claim forms monthly and they have to pay us. They do not even know how many we are at the clinic. They never ask themselves, what if we do not exist and they are paying ghosts? These people are meant to ensure that we have everything we need, but we have never seen their faces.

A concern about the issue of leave was also raised during the interviews. According to participants, they are not entitled to any leave except two weeks' leave in December (GI=11). Tension around this issue surfaced as some of the participants mentioned that they are being yelled at if absent from work, regardless of the reasons stated:

We are not allowed to take sick leave. If I do not go to work because I am sick, they will call, shout at me, and ask why I did not come to work. She [nurse] does not really care about us. They just want us to work and be at the clinic everyday. We are only humans, for heaven's sake.

#### 5.4 Shortcomings and gaps

While HBC has many benefits, it can often be limited because it is time and resource-intensive. One of the challenges facing volunteers was the unavailability of resources, including nursing kits and protective devices, especially latex gloves (GI=16). This situation was reported

to have a negative impact on HBCs' work, as they cannot effectively provide acceptable care to patients. Participants were also concerned about the fact that they alternatively use plastic bags as a replacement for latex gloves. The usage of plastic bags is believed to be demeaning and inappropriate:

The shortage of gloves is one of the major problems we are facing. We are told to use plastic bags to wash our patients, and a patient thinks he/she is disgusting, plastic bags are noisy and they scratch patients.

I worry that I might be infected with HIV, because plastic bags we are using sometimes have holes. We are risking our lives because we have to help our patient, but I think the Department of Health does not care about us. We need things like betadine, cotton wool, etc, but our priority is gloves.

The issue of patient transport was also one of the most important needs of HBCs. The majority, if not all, patients cared for by the volunteers are poor, cannot afford transport, and are too ill to walk to the clinic. As a result, HBCs have to organise transport for their patients to visit the clinic. This impacts negatively on volunteers, because they have to utilise their own funds to pay for patients' transport. All participants felt that government should provide patients with transport:

Most of our patients are very ill, cannot walk, and do not have money for transport. It breaks my heart to see my patients suffering, especially, when there is nothing I can do to help. Sometimes they even ask us to hire transport for them to go to clinic. The Department of Health should consider providing transport to very ill patients.

The implementation of the ART programme, coupled with an increased patient load due to the addition of patients in the ART programme, is felt to have placed a significant extra workload on HBCs. The majority of HBCs had more than ten patients each (GI=10) while others had none. The number of patients per home-based carer ranged between one and 19. HBCs felt that the nature and extent of the patient's health status should be taken into consideration when allocating patients to HBCs. HBCs suggested that those with patients on the ART programme and bed-ridden patients should have fewer patients. It was also reported that some of the HBCs find it difficult to attend to all patients due to the large number of patients under their care and the geographical distance between patients.

## 5.5 Expectations and experiences of HBCs — a poignant situation

Some kind of promotion, given the number of years dedicated as volunteers, was raised as one of their expectations. Volunteer HBCs are meant to receive a stipend of R500 per month for their volunteer work. Unfortunately, the allocation of these incentives did not take place in a standardised manner. Some of the HBCs qualify for stipends, but do not receive any. On the other hand, some used to receive stipends, but this was stopped without any explanation. This state of affairs created friction and dissatisfaction among the HBCs. Those not receiving any stipend felt that they should have fewer patients than those who are being paid. This matter clearly needs urgent attention.

HBCs also felt that they would continue with their job only if they were formally appointed in some capacity. All (GI=16) were dissatisfied with the monthly stipend; it is considered very little in terms of sustaining volunteers and their families. HBCs described that they enjoyed helping people and felt they were making a difference in people's lives, but regarded R500 as very little in view of the tasks they had to perform. Even though HBCs were cognisant of the fact that they were volunteers, they still felt that volunteer empowerment was of the utmost importance. As a matter of fact, the majority of volunteers were already looking for greener pastures outside the health system (GI=16).

HBCs mentioned that their caring activities caused exceptional physical strain; they suffered from physical exhaustion and fatigue due to the long distances they had to walk to patients' homes (GI=12). Participants also stated that they experienced psychological and emotional problems as a result of caring for patients. HBCs are often disturbed emotionally by watching the gradual deterioration in the condition of the symptomatic HIV/AIDS patients, as well as those with full-blown AIDS sliding towards death. Moreover, according to participants, the emotional effect is exacerbated when they have to bath bed-ridden patients, or help them to move from one place to another, and when the patient dies. It is for this reason that HBCs strongly stated a need for psychosocial support:

It is not easy to work with bed-ridden, patients because you have to be very careful when bathing them due to the fact that they have sores and blisters. After bathing a patient I have to change linen, it

is difficult, because when you try to move any part of the body, the patient feels pain and cries, I sometimes cry as well.

## 6. Discussion

The results strongly suggest that, despite progress and advocacy, uncertainty about the precise roles for HBCs remains, both at national and provincial level. *National Guidelines on Home-Based and Community-Based Care* (NDoH 2001) do not indicate the exact role of HBCs. The results point towards marked confusion about the roles of HBCs among the professional nurses, communities and HBCs themselves. As a result, nurses have expressed the desire for the roles of HBCs to be clarified with the introduction of the ART programme (Louwagie *et al* 2004). *National Guidelines on Home-Based Care & Community-based Care* (NDoH 2001) stresses the role of the family in providing care and support to ill family members. However, families have shifted their responsibilities for caring and supporting of ill family members to HBCs.

Unfortunately the guidelines are not clear as to what extent HBCs are to render their services to patients residing with family members. Furthermore, there seems to be an unrelenting and erroneous notion among the affected families that volunteers are being paid to care for the family in addition to the patient. This indicates that communities are not well informed in respect of HBC services. It is apparent that the issue of discrimination and stigma needs urgent attention, as it interferes with HBC service rendering. Moreover, there is a shortage of resources, especially home-care kits. The unavailability of home-care kits undoubtedly compromises the quality of HBC service rendering.

The study reveals a disconcerting variability in the amount, extent and quality of HBCs' training. It is evident that HBCs lack training, and do not possess sufficient skills to provide effective home care and support. In fact, volunteers lacked even the most fundamental skills needed for the provision of HBC and had insufficient knowledge about HBC. The fact that the majority of HBCs have patients on the ART programme, yet had no training in this regard, raises questions in terms of the quality of support offered by HBCs, and about the anticipated role of ensuring patients' adherence to treatment. This is not in accordance with the stipulations of the *Comprehensive Plan* which clearly stresses

the fact that HBCs should receive training to ensure patients' adherence to ART. Furthermore, HBCs do not have training on basic counselling; therefore, referrals are made to lay counsellors. Nonetheless, such an endeavour is apparently compromising confidentiality. It is strongly believed that efficient training would enhance HBCs' efficacy.

According to the *NGOs Policy*, no formal relationship exists between the Free State Department of Health and any individual or group of volunteers. Nevertheless, some HBCs believed that they were being paid by the Department of Health, and not by the NGOs. The policy further asserted that the Department of Health fund NGOs in order to pay volunteers, meaning that the Department expect NGOs to pay volunteers a monthly stipend. However, the allocation of stipends for HBCs is not handled in a uniform manner and the qualification criteria for HBCs are not applied consistently. It is clear that demands for stipends and dissatisfaction with the system divert attention from the ultimate goal of HBC in the ART programme.

Furthermore, the allocation of patients per HBC needs to be performed uniformly. Eventually, there appears to be inconsistencies in terms of what the policy says regarding the number of patients required per HBC. It is stated that each HBC should be allocated five patients at the most, while HBCs are presently caring for more than ten patients each (FSDoH [sa]). On the other hand, the *NGOs Policy* stated that there should be at least three patients per HBC. Moreover, concerning the ART programme, the norm or guideline originally set by the Free State is that there should be one HBC for every 12 patients on ART.<sup>9</sup> This in itself is indicative of discrepancies in terms of the policy.

The results of the study strongly reveal inconsistent support and supervision of volunteers by the Department of Health and responsible NGOs. There is confusion around the role of the NGOs and district coordinators in ensuring effective HBC. This exists over and above the clear roles and responsibilities vested upon NGOs by the *NGOs Policy*.

Perceptions of a lack of recognition by the Department of Health are having a negative impact on the effectiveness of HBCs in providing care and support. High attrition rates among volunteers are accelerated by lack of support and recognition of HBCs. The study also reveals

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serious communication problems between HBCs and professional nurses at the PHC facilities. According to the stipulations of the FSDoH, HBCs are entitled to four weeks leave per annum. In practice, however, this is not the case, as they are in fact given two weeks of leave, and only in the last month of the year.

## 7. Conclusions and recommendations

First and foremost, the study revealed gaps in policy implementation as far as HBC is concerned. Clearly, efforts are urgently required to ensure effective policy implementation. The success of the ART programme is heavily reliant upon community-health workers. Both the *Comprehensive Plan* and the *National Guidelines for Home-Based and Community-Based Care* strongly emphasise the role of HBCs in ensuring and monitoring patients' adherence to treatment. However, poor involvement of HBCs in the Free State ART programme is noted. Because ARV treatment is a logical extension of their current roles and responsibilities, the utilisation of HBCs as ARV treatment supporters is essential.

Although the *Comprehensive Plan* delineates HBCs' roles, these roles still have to be internalised by both nurses and HBCs alike. Most importantly, the respective responsibilities of the families themselves, and the roles of HBCs regarding the provision of care, should be made known to all concerned. The role and the responsibilities of the Department of Health and various NGOs concerning HBC have also not been sufficiently elucidated to HBCs. The support of CHWs as well as community mobilisation is essential to achieve the health promotion strategies and to confront HIV stigma and discrimination.

It cannot be denied that adequate supervision and support are essential to the success of HBC's activities. Furthermore, it is recommended that barriers to effective HBC in the ART programme could be addressed by:

- Reviewing and formalising different categories of CHWs, *ie* DOT supporters, ARV treatment supporters and HBCs, to ensure that their roles and responsibilities are clearly developed and rationalised.
- Clarifying and communicating the role of HBCs in the ART programme.

- Recognising and acknowledging HBCs as an essential part of the district health team.
- Providing support to HBCs, including the provision of adequate supervision, continuous training and psychosocial support.
- Providing the necessary resources to HBCs, for example home-care nursing kits, equipment and transport.
- Health personnel in general should be specifically orientated to understand the roles and functions of HBCs, particularly in the ART programme.

While findings such as those reported in this contribution are a cause of grave concern, they should be viewed as an opportunity to hear an urgent call for help and support.

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