

## Challenges impacting on the quality of care to persons living with HIV/AIDS and other terminal illnesses with reference to Kanye community home-based care programme

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### Abstract

HIV/AIDS has been found to be a challenging disease to humanity, its challenge spin-offs falling especially on to the caregivers of those infected and affected by the virus. This paper aims to discuss the challenges influencing the state of caregiving in the Kanye community home-based care (CHBC) programme in Botswana. The study was qualitative in design and explorative in nature, involving 82 primary caregivers in focus group discussions, and 5 CHBC nurses in individual interviews. Caregivers were found challenged by lack of community networks support, inadequate sanitary and care packages, poor shelter compromising privacy, inadequate income and food for their clients, inadequate care motivation as their volunteerism does not attract any payment, inadequate health personnel to offer psychosocial support like counselling, and an uncondusive caring environment generally. Putting in place policies to redress caregivers' poverty, helping caregivers start income-generating projects, increasing community assistance and caregiving facilities are recommended as factors to address caregiver challenges.

**Keywords:** *Poverty, community home-based care programme, HIV/AIDS clients, income-generating activities, incentives and motivation, quality of caregiving.*

### Résumé

Le VIH/SIDA s'avère être une maladie posant un défi à l'humanité, ce défi reposant tout particulièrement entre les mains des donneurs de soins aux personnes infectées et affectées par le virus. L'objectif de cet article est de discuter des défis influençant l'administration de soins dans le programme communautaire de soins à domicile de Kanye au Botswana. Il s'agissait d'une étude de conception qualitative et de nature exploratoire, impliquant 82 soignants principaux en réunions de groupe, et 5 infirmières de soins communautaires à domicile en entretiens individuels. Les donneurs de soins étaient confrontés à un manque de soutien de la part des réseaux communautaires, à de mauvaises conditions d'hygiène et à de mauvaises offres de soins, à des abris précaires, compromettant l'intimité, à des revenus et de la nourriture inadéquats pour leurs clients, à une motivation à soigner inadéquate étant donné que leur volontariat n'est pas rémunéré, à un personnel de santé inadéquat pour proposer un soutien psychosocial comme les consultations psychosociales et, d'un point de vue général, à un environnement de vocation sociale peu favorable. Il est recommandé de mettre en place des politiques visant à remédier à la pauvreté des donneurs de soins, d'aider les donneurs de soins à initier des projets rémunérateurs, de développer l'aide communautaire et les structures d'administration de soins, afin de répondre aux défis auxquels les donneurs de soins se trouvent confrontés.

**Mots clés:** *Pauvreté, programme communautaire de soins à domicile, clients souffrant du VIH/SIDA, activités rémunératrices, mesures d'incitation et motivation, qualité de l'administration des soins.*

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## Study rationale

The rationale of the broad study from which this paper is drawn was to assess the contributions of the caregivers in community home-based care (CHBC) programmes in Botswana, looking at the Kanye CHBC programme as a case study. The paper seeks to discuss the challenges influencing the current state of caregiving. The findings will suggest recommendations that will help bolster the state of caregiving, policy changes, and therefore improvement in the way people living with HIV/AIDS (PLWHA) and other terminal illnesses are taken care of.

## Operational definition

Operationally, the word caregiver refers to both the primary caregiver (family caregiver who stays with the sick person most of the time) and the community caregiver, also referred to as 'volunteer' in the Botswana context, who moves from house to house to help the primary caregiver discharge her/his caring duties. The researcher (and by extension the paper) does not wish to make any difference, as they are both out to assist in caregiving. However, only primary caregivers were interviewed (primary unit of analysis). The author also uses any of the three words 'client', 'sick' or 'patient' to refer to PLWHA and other terminal illnesses interchangeably. The researcher has operationalised the meaning of the word 'quality' by borrowing from Vuori (1982) (quoted by Ovretveit, 1992). According to Vuori, quality in care services (medical, social and psychological) refers to adequacy, which is supply in relation to needs. Therefore the quality of care is deemed to be adequate if sufficient of the necessary supplies as recommended by the Botswana Government care package is supplied to PLWHA and other persons with terminal illnesses, or *vice versa* (NACP 30, 1996).

## Introduction

Since the institutionalisation of the CHBC programme in Botswana (NACP 31, 1996), the caregiving programme has been elevated to complement the mainstream health system. Therefore, the issue of quality discharged by the programme has been a big issue. Since several studies have indicated poor performance of the programme, with a high death toll (DMSAC, 2004, 2005; Jacques & Stegling, 2001; Kangèthe, 2004, 2006), it has therefore been found necessary to study the challenges impeding or influencing the quality of caregiving in the programme. This paper discusses these challenges in the hope of impacting on policy and thereby improving the future operationalisation of the programme, and also the quality of the services.

According to Townsend (1979), the challenges of poverty manifest themselves as a multifunction of many factors,

like starvation, diseases, inability to achieve subsistence or minimum basic needs, deteriorating and deplorable living conditions, and inability to share and enjoy a decent standard of living. The United Nations indicates poverty or the state of being poor when one's living standards are below one dollar per day (UNDP, 1995). In caregiving contexts in Botswana, most of these characteristics of poverty are shared by most of the caregivers and their clients in the country. Even though many countries have generally had a period of economic and social growth since World War II, in many areas poverty and deprivations have remained persistent and important features of daily life (Ferge & Miller, 1987). While many areas of social development succumb to poverty and factors associated with it, one such conspicuous area is in caregiving, where poverty is largely the result of the impact of HIV/AIDS (Jackson, 2002; UNAIDS, 2005). This has been found to negatively compromise the quality of caregiving.

According to a BBC world news broadcast (2005), Africa's farming has progressively continued to deteriorate since the start of the HIV/AIDS epidemic. This is because HIV/AIDS has eroded the working capacities and productivity of communities, thereby threatening the food requirements of those living with the virus. This is because one of the requirements for a client in the care process to achieve positive living is the availability of a good diet. As HIV/AIDS takes an increasingly heavy toll on the lives of breadwinners, more and more families are affected by shortages of food and other necessities. This falls heavily on the primary caregivers who take care of the sick. The Food and Agriculture Organization (FAO, 2001) argues that people's nutritional status is determined by various factors, such as household food security, health and care. These are affected by HIV/AIDS. Page & Davies (1999), and the Food and Nutritional Technology Assistance Project (FANTA, 2000) suggest that HIV/AIDS aggravates the problem of poverty among households. This is attributed to the fact that morbidity and mortality reduce the time and human capital available to households (Ainsworth, 1993). A survey by Hope Worldwide NGO, South Africa, found that lack of food was the most pressing need besetting the caregiving process, the situation being exacerbated by the fact that the sick person may not desire what is available, but the body may demand that he be given special meals (UNAIDS, 1999).

In Botswana, most of the CHBC clients and their caregivers have been made poor and vulnerable by the HIV/AIDS phenomenon, and are therefore insecure as far as food is concerned. However, HIV/AIDS clients are entitled to a government basket of food. This is a food package given to vulnerable groups, like people living with the virus, the destitute and orphans, to complement their food needs and therefore mitigate the impact

of their vulnerability. The food basket is usually collected and administered by the caregiver. However, not all HIV/AIDS clients receive this benefit (Kang'ethe, 2004; NACP 30, 1996). There are many problems associated with the provision of these food baskets, such as lack of awareness by most clients and their families about the provision, stigma associated with the provision, and the long queues in the appointment system of the social workers to assess the socio-economic and ill health conditions of a client (Kalanke, 2004; Kang'ethe, 2004). Furthermore, the food basket, even when it is provided, is usually inadequate, given the ever-escalating rate of inflation in Botswana. The value of the basket at the time of research (December 2005 and January 2006) was P 233 (approximately \$ 40). In addition, the clients who get the basket sometimes complain of imbalance or over-representation of some food items over others. This is especially true if the contracted supplier does not have some food items at the time of collection. Poverty affects the caregivers of many clients but, ironically, no part of the food basket is set aside to help the caregiver, who may be just as vulnerable economically as the client (Kang'ethe, 2006).

The quality of most care programmes is dependent on their management. In Botswana it is usually elderly caregivers who manage most caregiving programmes. Most of these caregivers have a low or no educational background, yet the dynamism and challenges associated with caring for HIV/AIDS clients call for some relevant skills. With little or no skill, due to inadequate or no training, most of these caregivers are not able to ensure good-quality care (Kang'ethe, 2004; NACP 30, 31, 1996; Phorano, Ngwenya & Nthomang, 2005; UNAIDS, 2001).

Many research findings on the quality of caregiving in Botswana have found the quality compromised by inadequate care packages in the clinics. This is because of inadequate and unreliable supply of the resources. This has left many caregivers desperate, with no gloves, sanitation towels, bleach or incontinence sheets to adequately handle their clients. This also exposes the caregiver to contagion (Kang'ethe, 2004, 2006; NACP 30, 31, 1996). This, coupled with inadequate staffing to offer psychosocial support like counselling to both the client and their caregiver, only compounds the problem, further impacting negatively on the quality of care (UNAIDS, 2001).

## Methodology

A qualitative design was used in the study, including all the 140 registered primary caregivers in the programme, and the 4 CHBC nurses and their co-ordinator. Therefore, while registered primary caregivers formed the sampling frame, the primary caregiver formed the unit of analysis (Neuman, 1997; Rubin & Babbie, 1997). The response rate was 59%, with 82 volunteer

primary caregivers constituting 10 focus group discussions. The focus group discussions were conducted with the help of an interview guide. The 4 CHBC nurses and their co-ordinator were interviewed individually, using an interview guide that differed only slightly with the one for the caregivers. The role of the CHBC nurses was to corroborate, cross-check and confirm the responses of the caregivers.

To effect data analysis, the information from the focus group discussions with the primary caregivers and the one-on-one interviews with the nurses was audiotaped and then transcribed. The huge mountain of primary data was reduced to manageable categories and themes, forming the basis of analysis. This was made possible using quotes, analogies and proverbs, while tables and graphs were used to present the data and therefore infer the findings. To reduce data bias and ensure data reliability and validity, results from the pilot study findings acted as baseline data. There was double translation of the instruments, that is translation from English to Setswana and then from Setswana to English by two independent translators, the two parties coming together to settle any discrepancies. In addition, the 4 nurses and their co-ordinator answered more or less the same questions as the primary caregivers. The two interview guides differed only slightly, and the two sets of responses confirmed and cross-checked each other.

The caregivers' interview grouping selection was based on the clinic's proximity and point of service delivery, with some clinics having more than one focus group discussion. While caregivers' selection was done irrespective of their age and gender, the nurses' selection was based on their supervisory role to the caregivers. All appropriate ethical issues were taken into consideration: informed consent, maintenance of confidentiality, adequate debriefings before commencement, no coercion, and treating the respondents with due respect to maintain their integrity and their human rights. Withdrawal from the research was voluntarily allowed (Neuman, 1997; Salkind, 2000). Application by the researcher to carry out the research was made and approved by the Health Research and Development Committee (HRDC) board of the Ministry of Health's research unit.

Research was carried out in December 2005 and January 2006 in Kanye village, the biggest village in the Southern District of Botswana which, according to the Central Statistics Office (CSO) (2001), has a population of 40 628 persons. The village was chosen because it has numerous health facilities, including a big Seventh Day Adventist (SDA) hospital, which is used as a district referral hospital, 5 clinics and 2 health posts. (A clinic is bigger in terms of size of human resource and facilities, and serves a bigger population than a health post.) The Southern

District in which the programme lies had high HIV prevalence (25.8%) and the programme was experiencing a high death rate (DMSAC Report, 2004, 2005). The researcher was also the head of the HIV/AIDS programme for almost 5 years, and it was therefore necessary to document his experience and lessons learned.

## Findings

### Profile of the volunteer caregivers

#### *Age, gender and educational dimension of the caregivers*

The caregivers' ages ranged from 18 to 85 years. Forty-six caregivers (constituting 56% of the total caregivers) were older and obviously poor people of 50 years and above. A total of 28 caregivers (34%) were 60 years and above, 17 (21%) were aged between 60 and 69, while 10 (12%) were between 70 and 79 years old. Only 1 female caregiver was 85 years of age. The study revealed that most caregivers were women, and especially those above 60 years displayed characteristics of poverty – 88% of the caregivers had no any income to support themselves and were physically not strong enough to meet the caregiving demands, leading to their disillusionment with the caregiving role. Some caregivers broke into tears as they explained the circumstances of deprivation in which they worked. The relatively elderly caregivers especially indicated that they were psychologically drained by caregiving and that they needed to be assisted.

Regarding literacy, 74% of the caregivers had either never been to school or had only primary level education. Only 5% of the caregivers had tertiary education. Illiteracy was found to contribute to a low level of care, low productivity and poverty. This was psychologically disabling, as most of those who had never been to school were also elderly and had problems of accessing education on caregiving, following the medical and hygiene protocol, and following the disease progression of their clients (Atta & Fidzani, 1996; Kang'ethe, 2006). Findings indicate that the programme faces serious gender imbalances, with 80 (98%) being women and only 2 men (2%). Since women have other domestic chores, caregiving presented additional burdens and societal exploitation, further contributing to their poverty (Finch, 1984; Kelesetse, 1998; UNDP, 1995).

### Inadequate sources of income and food

Findings confirmed that many caregivers were poor, had no source of income, and therefore were not able to afford what their clients required or demanded. As many as 88% of the caregivers in the Kanye programme had no source of income, and they attributed their state of poverty and low quality of

caregiving to lack of engagement in any income-generating activity or any form of employment. The food basket, for those lucky enough to get it, was not adequate, as it had some food items over-represented while some were under-represented. Even for those scheduled to receive it, the social worker's assessment results took too long that caregivers were left with the challenge of looking for more income to supplement the food package. Lack of adequate food, therefore, presented one of the greatest stressors in caregiving, driving the caregivers further into poverty and compromising the quality of care, as they struggled to look for adequate food. This was exacerbated by the fact that the clients mostly required special and expensive food that caregivers could not afford. Caregivers, therefore, were frequently left with no alternative but to painfully watch their clients suffer, seeing them become weaker and more emaciated, not responding to ARV drugs due to food deficiency, and often succumbing to an array of opportunistic diseases (Kang'ethe, 2004). This scenario could partly explain the high death toll experienced in many CHBC programmes in Botswana, with the Kanye programme worst affected (DMSAC Report, 2005).

The quotes below were by caregivers demonstrating their desperation at their lack of income and food:

- *We are poor and have nothing else to do except caregiving.*
- *A patient does not understand. You give him/her the food you have, she/he refuses, yet you have no money to buy her/him what he/she wants as you are unemployed.*
- *It is not all the sick clients who get a food basket. Some of our clients have been waiting for the assessment results of the social workers for a long time in vain.*
- *Food is inadequate and does not meet the needs of the clients.*
- *The client wants good food, you give him/her thick sorghum porridge (motogo) (one of the common staple food for an ordinary Motswana), she/he vomits.*

### Inadequate sanitary facilities and shelter

Study findings confirmed that 41 (50%) caregivers had problems with sanitary facilities to provide a good and hygienic caring environment. This was because of poverty of the caregiver, the client and family members. Availability of water was especially important for caregivers of clients who were incontinent, but some caregivers did not have water in their compound, posing a big problem when washing clients and their clothing. This was a source of stress, and meant that the psychosocial support system was compromised, and the environment was not attracting people to come and give help because of the unhygienic conditions. Most caregivers confirmed that in such



circumstances, the CHBC volunteers (caregiver volunteers who are supposed to move from house to house assisting the clients) were even avoiding such clients. Some caregivers had the following to say:

- *We have no water in the compound because we have no money to connect because of lack of money.*
- *The volunteers (community caregivers) refuse to help some families, especially those with serious problems.*

As many as 70 caregivers (85%) complained that lack and unavailability of care package facilities like napkins, pads, cotton wool, bandages and gloves was a great stressor, especially to those caregivers who had incontinent clients. This increased the risk of contamination. Caregivers indicated having knowledge that some of them had succumbed to the virus through their caregiving, due to lack of caregiving knowledge and lack of care package facilities. The following quote attest to the inadequacy of care packages:

- *We are all going to die from contagion. We do not even know our status.*
- *How are we going to protect ourselves if the programme does not have protective facilities like gloves, napkins and many other things?*
- *The care package components are not adequate. Sometimes there is nothing.*

Lack of adequate space for caring was reported by 45 (54%) of the caregivers to be a stressor for both the primary caregiver, who was always with the client, and the volunteer (community caregiver), who usually visited the client and the family for any assistance:

- *Taking care in an environment where one does not have enough private space and privacy is really very stressful.*

This is because caring requires privacy. For the caregivers and their clients with inadequate space due to poverty, lack of toilets and other necessities, caregiving was an uphill and a very overwhelming exercise, which compromised the quality of care greatly.

### **Lack of material and financial provision**

All the caregivers in the Kanye programme complained of not being considered for any incentive or any form of payment for their caregiving assignments. The majority said their only source of motivation was the fact that they worked for their blood relatives and community members they knew well, as indicated by the following quotes:

- *We have accepted caring job because we take care of our relatives and members of our communities.*
- *No one else can do it. It is my community responsibility.*
- *It is my responsibility to take care of my son/daughter.*
- *It is my child. I bore him/her and have brought him/her up.*

Their caring strength, the majority of caregivers said, could be described by the proverb 'blood is thicker than water'. Caregivers said their poverty emanated from lack of a government policy to consider caregiving as an emotionally draining activity that should attract some form of incentives or payments.

### **Inadequate community support**

Sixty-five (79%) of the Kanye caregivers reported getting inadequate support, either materially, emotionally or financially from their relatives and families, neighbours, private individuals, grassroots traditional and political leaders, and other service delivery networks like NGOs and CBOs, and the community at large:

- *We do caregiving alone. Community members, relatives and family members only help a little.*

Caregivers therefore suffer the psychological problem of being neglected and abandoned to do caregiving with very little assistance. One caregiver indicated she was neglected by all the family members to go it alone:

- *I cannot get time to go and look for a job, as I'm alone caring for my father. They all [brothers and sisters] went for good, leaving me to struggle with caregiving [crying].*

This excessive and overwhelming burden, coupled with the number of clients per caregiver and lack of many other caregiving facilities, has driven many CHBC caregivers into dire poverty, and thus unable to provide quality care (Kang'ethe, 2004).

### **Discussion and recommendations**

Other research in Botswana complements the findings of this study that most CHBC programmes are gender skewed, mainly offered by elderly women who are usually challenged by poverty. A study carried out in Botswana by Munodawafa (MOH/NACP 41, 1998) found that all caregivers except one in Tutume were women, while in Molepolole, all caregivers were women. A study by Atta and Fidzani (1996) indicated that over 50% of caregivers in most of the Botswana CHBC programmes are elderly and poor women, the majority of whom have little or no education, making it difficult to follow the hygiene protocol in the care process or providing quality

care. It would seem that caregiving responsibilities in Botswana, as in many other developing countries, fall into the hands of the grandparents, particularly poor grandmothers. This explains the low standards found during the research study, with the situation being exacerbated by lack of care facilities (Ntozi & Nakayiwa, 1999; UNAIDS, 1999; WHO, 2002). The gender disparity, though a common phenomenon in many caregiving programmes in Africa and elsewhere, is a result of socialisation and needs to be dismantled so that both genders can support one another, as the burgeoning cases of AIDS are leaving female caregivers overwhelmed with little or no assistance. Education and advocacy targeting to achieve sharing of roles by both genders in caregiving need to be encouraged by government, civil society bodies and communities generally.

Findings that care programmes face income challenges and therefore resultant poverty is not a phenomenon faced by Kanye caregivers alone. In a study in Kweneng on caregiving by Mojapelo, Ditirafalo, Tau and Doehlie (2001), 85% of the caregivers were not employed and often cited poverty as a stumbling block towards provision of good care. The situation was made worse because most of the clients did not work. For instance, of the 30 clients interviewed in the above study, none was employed at the time of research, while in another study, still in Kweneng by Khan and Stegling (2000), glaring poverty was found among the caregivers, as evidenced by the lack of even the most basic necessities, with lack of food being the gravest. Of the 29 clients interviewed in this study, 24 had been employed before falling ill, but at the time of the study, only 2 were in paid employment. The main concern and anxieties of the clients was the future of their parents or young children after their death, while some were worried about the burden of care which they presented to their families, and the detrimental effect the disease had on the economy of their households.

The picture above in the study by Khan and Stegling (2000) and Mojapelo and colleagues (2001) is a demonstration of how HIV/AIDS impoverishes communities, the prevalent situation posing a serious challenge to the quality of care. However, thanks to current access and scale-up of free ARVs in Botswana it is anticipated that many clients will hopefully recover and continue with their daily routine activities. Nevertheless, access to ARVs in Botswana is still faced with the challenge of poverty and lack of food among the beneficiaries, to ensure effectiveness of the drugs (Agrinews, 2006, NACA, 2005). The government of Botswana, through its poverty reduction measures, needs to intervene and to introduce strategies that will ensure directing resources to the caregivers. The caregivers need to receive food packages alongside those of the clients. Empowering the clients and their caregivers through supporting them to start

income-generating activities (IGA) is the direction which the government campaign should be taking, coupled with commitment to ensure availability of care facilities in all health facilities. Currently this remains a glaring gap, calling for urgent address. Care-of-carers policies need to be developed and implemented, to ensure caregiver assistance in tandem with the assistance package to the clients. The achievement of Botswana in successfully meeting the WHO '3x5' target of providing at least its world quota of 50 000 clients with free ARVs by the year 2005 could be seriously undermined if these clients eventually succumb to death, after the heavy financial investment through ARV access (UNAIDS, 2001, 2005).

HIV/AIDS is poverty friendly, and many families beset by the scourge have been rendered poor as they struggle to give the clients what they require to continue living (Kang'ethe, 2004). Poverty has a deep psychological impact to the lives of caregivers, taking away their caregiving productivity, self-esteem and dignity (Nurses Association of Botswana [NAB], 2004). The socio-economic environment and frustration of the caregivers usually spills over to their clients, with the duo sometimes getting involved in conflicts and wrangles that further throw the caregiving arena into confusion with resultant low productivity (Dant & Gully, 1994; Kang'ethe, 2004). This is why professional counselling and debriefings need to be intensified in the caregiving arena (NAB, 2004). However, donors in the caregiving field, in collaboration with the government of Botswana, need to equip caregivers with income-generating projects to keep them busy and able to afford food for their clients. Advocacy by leaders of faith-based organisations should be increased, challenging communities to assist their sick people. This is one of the demands of Botswana's vision 2016, and societies and communities should aspire to achieve the vision tenets (UNAIDS, 2000; Vision 2016, 1997). NGOs and donors in the campaign field need to complement government efforts by helping the caregivers in nutritional education, finance, and starting nutritional gardens to grow food for themselves and their clients.

Lack of or inadequate food has contributed greatly to the poverty of caregivers and low-quality care generally. Research by Mojapelo and colleagues (2001) in Kweneng in Botswana found lack of food as one of the major factors impacting on quality of caregiving. Other research, also in Kweneng, Botswana, by Stegling and Jacques (2001) found food to be one of the problems negatively affecting caregiving. Driving and reinforcing the same food inadequacy concern for ARV clients, SADC Executive Secretary, Dr Salomao stated that the ARV rolls-out would not achieve desired results if food security was not adequately addressed. He commented that 'There is no

point in giving people ARVs on an empty stomach' (*Agrinews Magazine*, October, 2006). Across the board in many countries, especially of the developing world, lack of food has been found to negatively affect caregiving. In Namibia, for instance, a common complaint by community caregivers was that many families they attended to do not have food, making the caregivers feel obliged to share their own (UNAIDS, 2000). The government, NGOs in the caregiving field, the private sector and community members need to develop a strategy to meet the food demands of the clients. This is important, especially to clients taking ARVs that require special food. Thus, the heavy investment by the government of Botswana in ARVs could come to nought if the food concerns of the caregivers and their clients do not receive adequate attention.

Water to maintain cleanliness and an hygienic environment for the client is a basic human right, and a determinant of quality of care in the caregiving process. Lack of water, therefore, is a source of discomfort to the client and the caregiver and compromises the client's health, the healing process and the quality of care. This can lead to rapid progression of the disease. A study by Mojapelo and colleagues (2001) on caregiving revealed that some caregivers and their clients had neither piped water nor a toilet. The government, through poverty reduction funds, should connect water pipes free of charge to the homes of poor caregivers/clients without access to water, in order to ensure a good and hygienic caregiving process. Inadequate caring space due to poverty immensely affects the state of caregiving, thereby compromising the psychosocial and social support system to the clients. In the above study by Mojapelo *et al.* (2001), two of the clients lived in old derelict houses while one lived in a plastic shack, lacking in virtually all basic life conditions. The following are quotes from the Mojapelo study:

- *I am suffering because I am poor. I do not have anything to support my patient and myself with.*
- *We need more food and soap. I do not have any clothes for myself as well as my patient. We do not have a toilet, so we use our neighbour's.*

In circumstances like these, the fulfilment of the objectives of the CHBC programme in Botswana, of having the CHBC programme complement the hospital services in achieving decongestion of the sick, is cast in doubt, and calls for a wider debate on the place and quality of the CHBC programme. This situation could partly explain the circumstances and environments resulting in the high death toll experienced by clients in the Kanye programme (DMSAC Report, 20005) and low quality of care in the programme. In a human rights context, shelter, and by extension adequate sanitary facilities

are basic, and in the context of sickness, their provision needs to be prioritised to warrant some degree of privacy and care environment to the client and the caregiver (NAB 2004; UNAIDS, 2000, 2001; WHO, 1993). The government should have a fund to ensure that caregiving is handled in a decent environment that does not compromise the quality of care.

Unavailability of care packages and sanitation amenities, with the resultant risk of contamination and infection to caregivers, poses a human rights dilemma, as those who sacrifice to take care of others are themselves sacrificed by their volunteering activities. Other researchers have found that clinical waste management and disposal in many care programmes have also been problematic for the caregivers. This is due either to the lack of a viable policy, or failure to operationalise it, inadequate community education on the subject and neglect, and lack of adequate facilities leading to unprofessional and ineffective ways of disposal and handling. This has given rise to subsequent hazards that compromise the quality of care in the programmes (Mokgwaru, 2001). A number of diseases and infections, including HIV infections, have been documented to be transmitted by mere contact with body fluids, secretions of patients and hospital wastes. Improper disposal of clinical or hospital waste could be catastrophic to the health and well-being of the community as well (Panos Institute, 1990; Singh, Tabish & Malviya, 1990; Norvish, 1987). This is especially due to lack of proper government machinery to ensure availability of care package facilities in medical health institutions, and also due to lack of money to provide these (Jacques & Stegling, 2001; NACP 30, 31 1996).

Lack of material and financial provision to motivate and incentivise caregivers to provide quality caregiving has been responsible in many instances for the poverty of the caregivers. Ironically, when community support programmes are developed to serve people who are terminally ill, especially in Botswana, they tend to rely on women as unpaid caregivers, who may be poor or poorer than the people they are assisting. They receive neither stipends nor incentives, despite the overwhelmingly difficult duties, the situation reflecting on the quality of care they are able to supply (UNAIDS, 2000, 2001). The report of the United Nation's Secretary General's Task Force on women, girls and HIV/AIDS in South Africa points out that there is little recognition or compensation for caregivers who may be subjects of exploitation and severe stress (<http://www.unfpa.org/hiv/women/report/chapter4.html>).

In Botswana, the issue of supporting the caregivers has not been appropriately addressed. While the government has instituted programmes to assist HIV/AIDS clients, no coherent programmes exist to assist the caregivers, in the form of

financial or material resources. Therefore, lack of the material resources necessary to help clients and caregivers has been a great stress for the caregiving process. Frequently, there are insufficient resources, such as medication and supplies, to meet the needs of the clients. This no doubt affects the work of the caregiver and renders him/her ineffective (Kang'ethe, 2004; NAB, 2004). Feminists have expressed their dissatisfaction with women caring for the sick without any remuneration, throwing them into a deeper pit of poverty and exploitation (Finch, 1984; Kelesetse, 1998). Kelesetse (1998), for example, sees women working in CHBC programmes as a process of gender exploitation, making them ever poorer. Mathebula (2001), in a seminar paper examining the experiences and needs of caregivers in Botswana, revealed that caregivers in Botswana experience many difficulties and have many needs that are related to lack of finance, professional support and assistance. This has compromised the caregivers' output in many respects. Caregivers frequently cited lack of money for transport to visit sick clients, or to fetch and pay for drugs, or buy paper and pens for record-keeping, or rubber gloves for handling sick clients, as some of the principle causes of stress, undermining their ability to do their work adequately (UNAIDS, 2000).

The author sees the provision of incentives as one of the ways to raise caregiving morale to improve the conditions in caregiving. According to Huczynski (1987), the purpose of an incentive or reward is to facilitate positive changes or behaviour that result in increased productivity. However, making rewards consistent with the caseload is one of the major organisational challenges for caregiving programmes. While an appropriate reward system contributes to organisational health and productivity, inappropriate reward systems sabotage and kill morale, resulting in lowered productivity. Lack of incentives, the research respondents reported, was a pivotal reason why caregiving does not attract young women and men. Botswana needs to learn from neighbouring countries that have addressed this issue. In Namibia, for instance, caregivers are given minimum support through Christmas and Easter bonuses, a funeral policy, ongoing training, and the allocation to each caregiver of N\$100 per month, as a token of reimbursement for whatever the caregiver has spent in performing caregiving duties. Most caregivers pool these payments in order to bulk-purchase washing soap or staple foods to be divided equally among the members (UNAIDS, 2000).

In Zimbabwe, Chirumhanzi CHBC caregivers receive as an incentive, a year's pocket money in a lump sum. Workshops and

monthly meetings where they get a good meal and an opportunity to interact with one another also serve as an incentive to their work. Caregivers working at the Hillcrest AIDS Centre on the outskirts of Durban, South Africa, receive a monthly supply of basic foods, including mealie meal, beans, rice, sugar and tea after 6 months' satisfactory service (UNAIDS, 1999).

Inadequate community support has greatly contributed to caregivers being overwhelmed and downtrodden. Studies done in Kweneng, Botswana on caregiving by Khan and Stegling (2000) and by Mojapelo *et al.* (2001) found that caregivers felt unsupported by their families, relatives and the community at large, and were working in a sea of poverty; while research findings in Zimbabwe on caregiving suggest that care programmes are not supported by their communities. For example, the Chirumhanzi CHBC in Zimbabwe is not supported by community chiefs (UNAIDS, 1999). The current call by the Botswana government for communities to cherish and work to fulfil Botswana's vision 2016 through one of the vision pillars 'being a just, caring and compassionate society' is a call for people to value and inculcate the spirit of helping one another (Vision 2016, 1997). This could reduce the poverty inherent in today's caregiving process, and therefore raise the quality of care. However, according to Mensah (1994) and Brouard (quoted in UNAIDS (2000), lack of community assistance presents a departure from past practice, when community networks afforded material, financial and emotional help to their sick people. In Botswana, the concept of working together, i.e. *letsema* was well embraced, and involved participation and encouragement from traditional leadership structures. Advocacy and lobbying need to be strengthened to return to these values (WHO, 2002).

## Conclusion

HIV/AIDS has impoverished communities, with a heavy load falling especially on the caregivers. Policies and programmes need to be put in place to address the poverty of the caregivers if the CHBC programme is to deliver good-quality care. Putting in place income-generating projects, ensuring adequate provision of care facilities, and considering incentives through government, NGOs or donor communities, as is done in many other caregiving settings in other countries, could help redress the challenging environment of the caregivers. Community assistance by all could serve as a means of reducing the poverty of the caregivers. Ample education to ensure that the gender gap and disparities are reduced would go along way towards easing the burden on female caregivers.



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