

# Analysis of the burdens of caregivers providing care to people living with HIV/AIDS in Botswana

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## Abstract

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**Background:** Caregivers, when providing care under the community home-based care (CHBC) programme, experience many burdens of a physical, emotional, financial or social nature. However, these problems are hardly ever considered by the planners of CHBC programmes. A comprehensive overview of the experiences of caregivers is desirable to help policy makers and public health planners formulate intervention measures to address caregivers' burdens.

**Methods:** The sample size calculator programme that allows for 95% confidence (and an error margin of 4%) was used: the estimated sample size for the study was 272. This number was derived from the eight sampled CHBC groups using probability proportional to size. Simple random sampling was employed in identifying the specific caregivers to be interviewed. Questionnaires were administered on this selected sample at their homes or CHBC headquarters by trained research assistants who ensured that all ethical considerations were observed. In the end, 169 caregivers responded within the study period.

**Results:** The study shows that very little support is given to caregivers. In addition, while men's burdens are mainly economic, those of women are overwhelmingly emotional. Furthermore, there is an insignificant association between caregivers' expected and received support while providing care to people living with HIV/AIDS.

**Conclusion:** The study concludes that, to reduce caregivers' burdens, a comprehensive CHBC programme, that will ensure that the role of CHBC caregivers is adequately recognised by the government and community, is needed.

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## Background

Botswana is one of the countries hardest hit by the HIV/AIDS epidemic. Currently, the population-based prevalence rate of 17.1% is one of the highest in the world.<sup>1</sup> However, the figure shows a significant drop from the adult prevalence rate of 37.3% at the end of 2003, when 330 000 adults were known to be living with the disease and with about 33 000 recorded deaths due to AIDS.<sup>2,3</sup>

As it became increasingly difficult for the public health system to provide care and support for the increasing number of HIV cases, the Government of Botswana in 1995 adopted community home-based care (CHBC) as a model to provide care and support for people living with HIV/AIDS (PLHIV/AIDS) in their homes. Family members, neighbours and friends undertake this role as a matter of necessity. The majority of these people have been known to be women and girls (often children and grandmothers).<sup>4-7</sup> This places an extra burden on women and girls who, in most cases, are scantily rewarded. Just as it is the desire of the

international community and various national governments that PLHIV/AIDS have the right to care of high quality, it is also important that caregivers be valued and supported and receive substantial compensation for the time and effort they put in to deliver care to PLHIV/AIDS.

Pakenham and Dadds<sup>8</sup> used the term 'caregiver burden' to describe the physical, emotional, financial and social problems associated with caregiving, which can be assessed in terms of objective or subjective impact. Objective impact assesses the extent to which caregiving disrupts daily routines and social relationships and negatively affects resources.<sup>9,10</sup> It includes forced changes in household routines, missed days of work, family friction, reduced social contacts, loss of income and reduced energy.<sup>11</sup> Subjective impact assesses the caregiver's perception of and reactions to caregiving demands.<sup>9,12</sup> Such perceptions include feeling trapped by caregiving, feeling nervous or depressed about the relationship with the patient, or even resenting caregiving tasks.

Under the CHBC programme, caregivers have been classified as primary caregivers (family members or relatives of the client) and volunteer caregivers (community members or friends and neighbours).<sup>13,14</sup> Caregivers are not professional care providers but the services they provide, though restricted, save the government a great deal of money. Volunteer caregivers visit the homes of sick people and provide basic nursing services, counselling, health education, nutrition monitoring and some psychosocial support, while taking precautions to prevent the spread of HIV. Volunteer caregivers (who are not paid) are usually recruited from the communities and trained on basic principles of caregiving, including nursing care. Some of the basic nursing services rendered include cleaning wounds, treating sores, providing mouth care, turning clients to lie on their other sides, assisting clients with toileting, visiting health facilities to obtain medication and reminding clients to take their medications.<sup>14</sup> The volunteers also assist the families of clients through training in basic skills, especially on how to grow vegetables and how to become primary caregivers.

CHBC is rooted in the principle of preservation of traditional caring patterns, which encourages families to take responsibility for sick members. Care for clients with HIV/AIDS in the home enables families and communities to be actively involved in their care. Traditionally, parents, spouses, grandmothers and adult daughters have been caregivers of people with terminal illnesses.

The caregiver's burden can, usually, be related to some or all of the following factors: (i) The caregiver is expected to play an unexpected role.<sup>15,16</sup> (ii) Caregivers (primary and volunteer caregivers) sometimes work for 24 hours a day. They might be required to perform multiple and sometimes conflicting roles that require nursing skills and meeting their own home and work obligations. This can lead to physical exhaustion. (iii) Sometimes caregivers are relatively young and could become emotionally distressed by caring for someone who has a terminal illness. (iv) Many families pass through severe economic stress when the breadwinner suddenly falls ill, making it difficult to meet family needs. In such situations, caregivers sometimes are compelled to assist the family of the client financially. This loss of income can make it difficult for caregivers to meet their personal needs. (v) The stigma surrounding HIV/AIDS can be a burden to caregivers. The attitude of the community in rejecting HIV-positive individuals because of the disease and its mode of transmission affects caregivers' incentives to provide care. (vi) Parents of HIV-positive children additionally face the challenges of organising care for their children, worrying about the needs of those who are sick and those who are healthy, trying to help their children cope with the disease and facing possible stigmatisation from the community.<sup>17</sup> All these factors increase the burden of caregivers.

This study, which was undertaken between June and September 2008 with funding from the Office of Research and Development, University of Botswana, examined the opinions, of a stratified sample of 169 caregivers, on the psychosocial, emotional and financial burdens that they experienced in providing care, their expectations in terms of support in performing their role as caregivers and the extent to which these expectations were met. Furthermore, it determined the extent of the burdens caregivers experienced in caregiving. Ama and Seloilwe<sup>14</sup> have shown that caregivers invest almost their whole income in assisting clients and their families during caregiving. This adds to caregivers' burdens. A comprehensive overview of the experiences of caregivers is desirable, as this will help policy makers and public health planners to formulate intervention measures to address the impact of caregiving on caregivers, recognise the role of and need for support for caregivers and develop appropriate policies to improve the CHBC programme in Botswana.

## Methods

### Design

The study was cross-sectional and covered four health districts and eight CHBC groups in Botswana. Quantitative methods were used in obtaining information from the caregivers. A three-stage stratified sampling method was used in the study. The health districts, CHBC groups and caregivers constituted the three strata. From the 16 health districts that had established CHBC, 25% ( $n = 4$ ) were selected for the study. Allocating this number of districts proportionately to urban-rural distribution (four urban districts and 12 rural districts; 1:3) gave one urban district and three rural districts for the study. However, in order to be able to compare results among the urban districts as well as the rural districts, the distribution was purposely adjusted to two urban and two rural districts. Two urban districts (Gaborone and Selibe Phikwe) and two rural districts (Bobirwa and Kweneng East) were randomly selected from the list of the four urban and 12 rural districts, respectively. As Mugo<sup>18</sup> states, "This combination of various sampling strategies achieves the desired sample. This helps in triangulation, allows for flexibility, and meets multiple interests and needs." The method fitted the purpose of the study, the resources available, the question being asked and the constraints being faced, and did not create any problems in analysis.

From each of the sampled health districts, two CHBC groups were randomly selected and a list of caregivers that was obtained from the CHBC coordinators in each district formed the sampling frame for the study. The statistically determined sample size of caregivers for the study (see setting and sample) was allocated to the eight CHBC groups using proportional allocation to size, and the caregivers to be interviewed were randomly selected.

### Study questions

- (i) What are the major burdens that caregivers experience while providing care to PLHIV/AIDS?
- (ii) To what extent do caregivers experience these burdens?
- (iii) What are the expectations of caregivers in terms of support in providing care, and to what extent are these met?

### Setting and sample

This study was conducted between June and September 2008 and was supported by funding from the Office of Research and Development, University of Botswana. It targeted 498 caregivers from the eight sampled CHBC groups. The sample size calculator programme<sup>19</sup> that allows for 95% confidence (and an error margin of 4%) and that posits that the response from the sampled population would be the same as that of the entire population was used; the statistically determined sample size for the study was 272. This number was allocated to the eight sampled CHBC groups using probability proportional to size. Simple random sampling, using the list of caregivers kept at the CHBC offices as the sampling frame, was employed in identifying the specific caregivers to be interviewed.

### Instruments used for the study

The research instruments used in this study were the questionnaire developed by the authors, experience drawn from relevant literature<sup>20</sup> and a semi-structured interview guide. The questionnaire contained questions about the caregivers' demographic characteristics, their opinions on the burdens they experienced while providing care, the extent to which they experienced these burdens, the expected support in providing care and the extent to which these expectations were met. Answers to some of the questions were provided on a four-point scale; in other cases, the questions required the caregivers to respond with "yes" or "no".

### Psychometric properties of the questionnaire

The quality and content validity of the questionnaire was assessed by staff in the nursing and statistics departments at the University of Botswana, while the staff of the CHBC programme of the Ministry of Health, Botswana assessed the protocols for the use of appropriate terminologies and the appropriateness of selected groups in the sample to be studied. The questionnaire was later tested on a sample of 20 caregivers selected from a CHBC group in Gaborone, different from those to be studied, for content validity and quality and internal consistency. The Cronbach alpha was calculated as 0.89.

### Data collection

The questionnaire was administered to the sampled caregivers by trained research assistants at their homes or at the CHBC offices. Data were collected from 169

caregivers (about 62% of the targeted sample), because some were reluctant to participate in the study and some were not available, even after several visits by the research assistants within the period of the survey. This response percentage is reasonably high and much higher than that obtained by Servick et al<sup>21</sup> (19.7%) and, according to Keeter et al,<sup>22</sup> creates insignificant problems in the analysis of the results (see also Visser et al<sup>23</sup>). The interview guide was used in collecting information from the coordinators of the CHBC groups on caregivers' perceived experiences.

### Ethical consideration

The Health Research Committee of the Ministry of Health, Botswana, considered and approved the protocols for the study as meeting all ethical considerations. The purpose of the study was explained to the caregivers by trained research assistants before questionnaire administration. The caregivers were informed that participation in the study was voluntary, that there was no payment for participation and that they were free to withdraw from participating at any time. They were assured of the confidentiality of the information obtained as the questionnaire was coded to ensure anonymity. Each caregiver willing to participate in the study gave written consent.

### Data analysis

Data were captured using the Statistical Package for the Social Sciences (SPSS) computer program. All variables, including the responses to the open-ended questions, were coded before being captured using the programme. Data were analysed using descriptive measures, such as percentages, means and standard deviation, and inferential statistics, such as the t-test. Factor analysis was used to delineate the variables that were contributing more to female or male burdens in caregiving. Graphical representations helped to illustrate the results obtained further.

## Results

### Characteristics of caregivers

Of the 169 caregivers who participated in this study, 91% were female and 9% were male. A little over 50% were older than 40 years and about 39% were older than 50. Forty-four per cent of the caregivers were in the range of 21 to 40 years. The majority of the caregivers (73%) were volunteers, while 27% were primary caregivers. About nine in every 10 caregivers (93%) had secondary school certificates or less. Forty-three per cent of them had been trained to provide care. While 77% of the caregivers were unemployed, 23% were employed. An overwhelming majority of the caregivers (91%) earned a monthly income below P1 000 (about US\$140) and about 57% had provided care for, at most, four years.

## Caregivers' burdens

In order to determine the impact of caregiving on caregivers, the sampled caregivers were asked to indicate the burdens they experience on a number of issues related to their caregiving services. The burdens cited (see Figure 1) by over half of the caregivers can be classified as follows:

**Physical:** Back pain and feeling of illness (headaches, stomach problems and common cold).

**Emotional:** Disrupted sleep as a result of caregiving; inability to keep their minds on what they were doing; worry about who will care for the caregiver when she or he becomes ill.

**Social:** "Felt I couldn't leave my relative or client alone"; community rejection of HIV patients; inability of caregiver to muster support from family and social network.

**Financial:** "Caregiving affects my resources negatively."

Never being relieved by other caregivers or family members, the feeling that caregiving was taking the caregiver out of her/his work, the interference of caregiving in the caregiver's social relationships and risks of infection were cited as the less stressful experiences.

## Gender differences in burdens of caregiving

The factor analysis method with the principal component analysis extraction method was used to delineate the gender differences in the caregivers' expressed burdens (see Table 1). In the case of the male caregivers, six factors were extracted, which accounted for 86% of the total explained variance of the factor loadings. Seven factors were extracted for the female caregivers, accounting for 77% of the total variance. Table 1 summarises the component matrix for the most highly weighted factors each, for male and female caregivers. The analysis shows that the

most important variables (having the highest correlation, of between 0.80 and 0.88 with underlying factors) that explained men's burdens were the following: felt that caregiving was taking him out of work, felt that caregiving affected his resources negatively, felt torn between work and family responsibilities, had back pain, felt ill (headaches, stomach problems and common cold), felt dissatisfied with the support from his family and had sleep disrupted because of caregiving. These variables are heavily loaded on factors 1 and 2 (economic factors), accounting for 58% of the variations in those factors. On the other hand, the most important variables explaining women's burdens were the following: had never been relieved by someone else, felt scared about the risk of infection, had sleep disrupted because of caregiving, experienced guilt, helplessness and hopelessness about the imminent and frequent death of patients, worried about who would care for her when she became ill, worried about community rejection because of disease or mode of transmission and worried about her inability as caregiver to obtain support from family and social network. These variables are heavily loaded on factors 1 and 2 (emotional factors), explaining 47% of the variation in those factors and with correlation between the variables and the factors lying between 0.80 and 0.96.

## Extent to which burdens were experienced

The caregivers were asked to indicate on a four-point scale (1 = To no extent; 2 = To some extent; 3 = To a great extent; and 4 = To a very great extent) the extent to which they experienced burdens while providing care to PLHIV/AIDS. The results of the responses are summarised in Figure 2, with the scales "To a great extent" and "To a very great extent" collapsed into one.

Figure 2 shows that the majority of the caregivers (82%) experienced difficulty in the management of increased cost of living to either a great or very great extent. Other highly rated burdens were loss of income due to caregiving (70%), tearfulness in seeing the client go through the pains of death (66%), sleeplessness (63%) and the increased stigma associated with HIV/AIDS (60%). Feeling resentment in providing care was not a burden to a substantial number of caregivers. Forty-nine per cent of the caregivers indicated that they experienced this feeling to no extent.

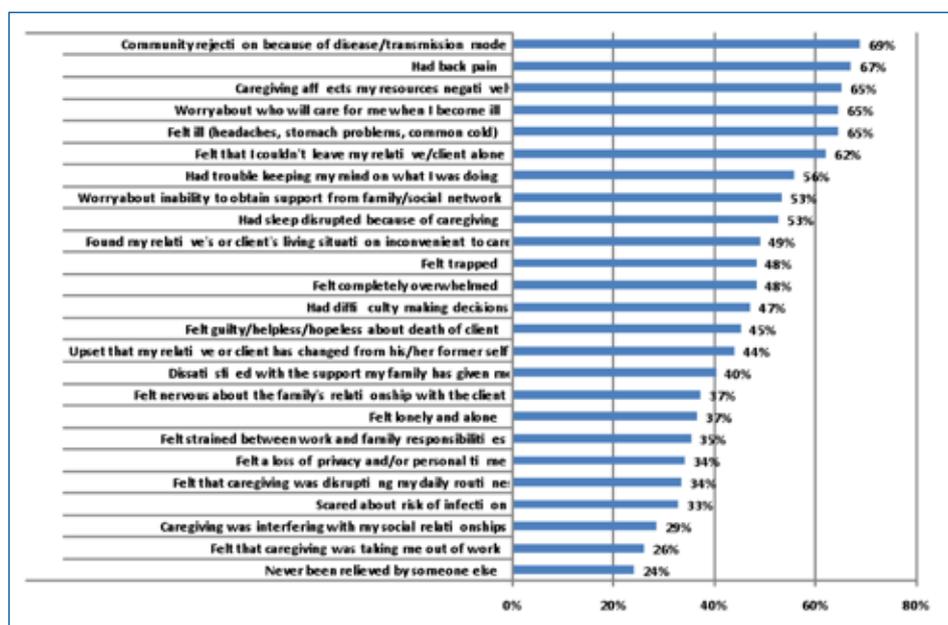


Figure 1: Percentage of caregivers who experienced certain psychosocial and emotional burdens

Table I: The factor analytic component matrix showing gender differences in expressed caregiving burdens

Variables	Component matrix			
	Male		Female	
	1	2	1	2
Had trouble keeping my mind on what I was doing	0.44	-0.49	0.00	-0.13
Felt that I couldn't leave my relative/client alone	0.44	-0.49	-0.20	<b>0.60</b>
Felt that caregiving was disrupting my daily routines	0.70	0.27	-0.02	<b>0.59</b>
Felt that caregiving was taking me out of work	0.13	<b>0.81</b>	-0.04	-0.13
Caregiving was interfering with my social relationships	0.58	0.29	-0.01	0.55
Caregiving affected my resources negatively	<b>0.88</b>	-0.29	-0.20	<b>0.76</b>
Felt completely overwhelmed	0.72	0.14	-0.19	<b>0.61</b>
Felt lonely and alone	0.56	-0.01	-0.23	0.45
Was upset that my relative/client had changed from his/her former self	0.55	0.16	-0.20	0.58
Had difficulty making decisions	0.77	0.31	-0.07	<b>0.72</b>
Felt trapped	0.77	0.31	-0.23	<b>0.65</b>
Felt nervous or depressed about the family's relationship with the client	0.69	0.40	0.05	-0.13
Felt torn between work and family responsibilities	0.13	<b>0.81</b>	-0.02	-0.15
Found my relative's/client's living situation inconvenient	0.59	-0.10	-0.02	<b>0.70</b>
Had back pain	<b>0.82</b>	-0.39	-0.17	<b>0.76</b>
Felt ill (headaches, stomach problems and common cold)	<b>0.82</b>	-0.39	0.01	-0.09
Dissatisfied with the support my family has given me	<b>0.84</b>	0.05	-0.20	0.47
Have never been relieved by someone else	0.51	-0.16	<b>0.81</b>	0.15
Scared about risk of infection	0.36	0.35	<b>0.81</b>	0.15
Had sleep disrupted because of caregiving	<b>0.87</b>	0.28	<b>0.96</b>	0.17
Felt a loss of privacy and/or personal time	0.79	0.25	<b>0.64</b>	-0.01
Experienced guilt, helplessness and hopelessness about the imminent and frequent death of patients	0.54	0.02	<b>0.96</b>	0.17
Worried about who would care for me when I became ill	0.59	0.27	<b>0.96</b>	0.17
Worried about community rejection because of disease or mode of transmission	0.79	-0.53	<b>0.96</b>	0.17
Worried about my inability as caregiver to obtain support from family and social network	0.79	-0.53	<b>0.96</b>	0.17

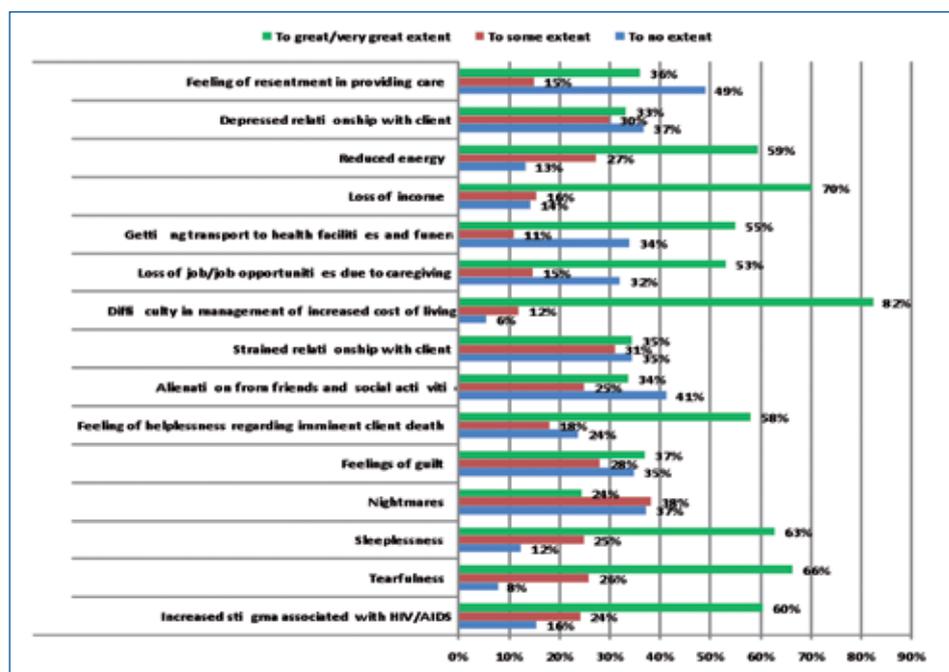


Figure 2: The extent to which caregivers experienced burdens while providing care

### Expectations of caregivers

Because it could be assumed that caregivers, though volunteers, had certain expectations in terms of support from the government and particularly the Public Health Care Department of the Ministry of Health, Botswana as they took up the mantle of providing care to PLHIV/AIDS, caregivers were asked to indicate what their expectations were and to what extent these expectations were met as they provided care. The results are summarised in Figure 3. The figure shows that visits by support groups (93%) were the support most anticipated by the caregivers. Other types of support expected included

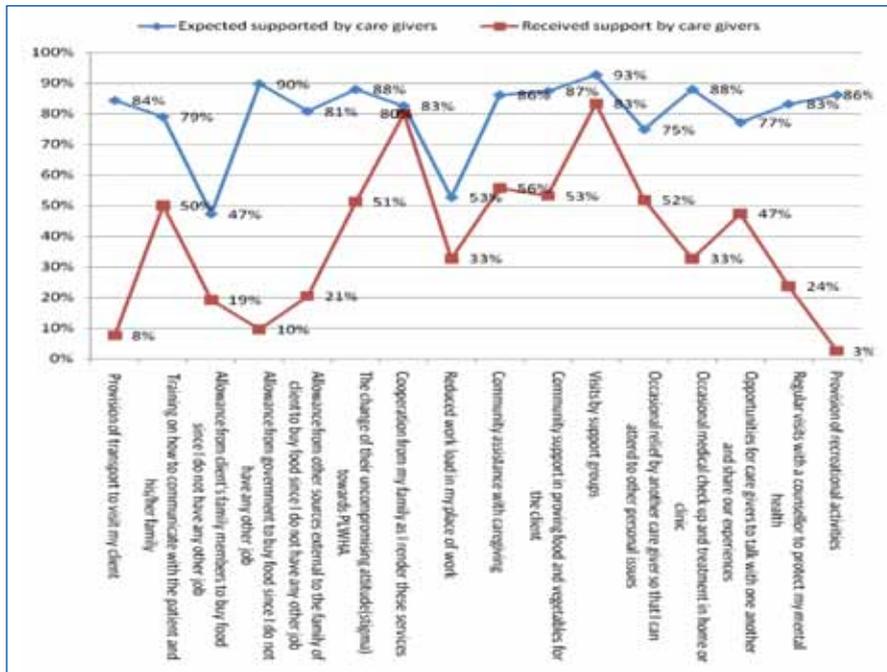


Figure 3: Caregivers' expected support and the extent to which this support was received

an allowance from the government to buy food since they did not have any job (90%), change in the community's uncompromising attitude towards PIHIV/AIDS (88%), occasional medical check-up in the home or clinic (88%), community support in providing food and vegetables for the client (87%), community assistance with caregiving (86%) and provision of recreational activities for the caregivers (86%). However, the expectations of the caregivers were hardly ever met in any of the mentioned areas. Eighty-three per cent of the caregivers indicated that they were visited by support groups, while 80% had the co-operation of their family members as they rendered caregiving services. Only 33%, 10%, 8% and 3% of the caregivers said they received an occasional medical check-up in their home or clinic, received an allowance from the government to buy food, were provided with transport to visit their clients and were provided with recreational activities, respectively. There is very little association between the expectations of the caregivers and the meeting of these expectations by the public health care system (correlation coefficient,  $r = 0.203$ ;  $p > 0$ ).

## Discussion of results

The decision to become a caregiver is usually prompted by certain circumstances. For instance, when a family member, a close friend or a neighbour suddenly falls ill, one is compelled to offer assistance in the form of financial aid, encouragement or performance of certain household chores. The opportunity costs for such care provided are the time spent in providing care, emotional and physical exhaustion and sometimes denying oneself certain social and financial benefits.

The study has shown that very little support is given to caregivers, who are predominantly women in this study, by the government, private sector and communities in terms of provision of allowances for food, health care services, recreational activities and even transport to the clients' homes. These are indications of the lack of recognition of the role of caregivers, fair financial support and appropriate standards of support for caregivers under CHBC and are likely to contribute to the burdens of caregivers.<sup>4</sup> These findings point to the UN Global Coalition on Women and HIV and AIDS report in 2004,<sup>2</sup> which called for a Volunteer Charter to address the burden of care on the community, and in particular on women, and that not only respects community caregivers but also standardises working hours and introduces remuneration, psychosocial support and other tangible protection.

The caregivers' main burdens have been categorised into physical (back pain and illness, such as headaches, stomach problems and common cold), emotional (disrupted sleep as a result of caregiving, inability to keep their mind on what they were doing and worry about who will care for the caregiver when she or he becomes ill), social (feeling that the caregiver couldn't leave the relative or client alone, community rejection of HIV patients and inability of the caregiver to muster support from the family and social network), and financial (caregiving affects resources negatively). These findings are supported by O'Neill and McKinney<sup>11</sup> and Pakenham and Dadds,<sup>8</sup> who also categorised the caregivers' burdens as physical, social, emotional and financial and included forced changes in household routines, missed days of work, family friction, reduced social contacts, loss of income and reduced energy. In addition, a gender analysis of the caregivers' burdens reveals that, while men's major burdens are economic, those of women are mainly emotional and hinge on worries and feelings of guilt, characteristics demonstrated in women's care for the home and family members.

Difficulties in the management of increased cost of living and loss of income were experienced to a great or very great extent by the caregivers. These findings are connected with the fact that the majority of caregivers were unemployed and 91% of them had a mean monthly income of about US\$140. In addition, this problem is exacerbated by the little or no financial support, compensation or remuneration to caregivers by the government and community. Currently, the Government of Botswana gives a monthly allowance of US\$15.26 to each caregiver, and this allowance is not evenly

distributed as caregivers in some rural health districts do not receive it.<sup>15</sup> Moreover, caregivers are compelled by love for the client and family to spend their resources to buy food for the client, transport him or her to the hospital/clinic to collect medication and contribute to the funeral expenses of the deceased.<sup>14</sup>

There are several limitations to this study. The study covered only eight CHBC groups selected from four health districts in Botswana. Although appropriate methods were used to collect the data, the study is limited in its scope. The study relied on information provided by caregivers. All the analyses in the study have been made on the assumption that the information provided was accurate and reflected the true perceptions of the caregivers. The authors acknowledge that the results of the study are based on respondents' supplied information from eight CHBC groups selected from four health districts. Interpretations of the results are, therefore, limited to the study areas, but the results do provide strong reasons for extending the study to other CHBC groups in the country. Because of budgetary constraints, a focus group discussion (a qualitative approach) could not be concluded, which would have shed additional light on some of the psychosocial issues in the study.

## Conclusion

In the light of the findings from this study, the authors conclude that, in order to ensure that the burdens of caregivers are reduced, there is a need for a comprehensive CHBC programme that will ensure that:

- The role of caregivers in CHBC is adequately recognised by the government and community; and
- There is improved support for caregivers, which will include psychosocial support (care for caregivers); adequate remuneration for the work caregivers are doing, in terms of increased allowances, salaries or stipends; training on how to communicate with clients and administer some first aid treatment; and provision of transport for caregivers to visit their clients.

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## References

1. National AIDS Coordinating Agency (NACA). Botswana AIDS Impact Survey II: Popular Report, Gaborone; 2005.
2. UNAIDS. Facing the future together. UNAIDS Regional Support Team, East and Southern Africa, Sunninghill, Johannesburg, South Africa, 2004:19.
3. Integrated Regional Information Network (IRIN): Botswana-country profile: epidemiological fact sheet (updated Feb 2005). Plus News, Tuesday June 20, 2006. Available from <http://www.plusnews.org/AIDS/botswana.asp> (Accessed 27/06/2009).
4. Chella A. Reducing the burden of HIV and AIDS care on women and girls: VSO policy brief 2006. Available from [http://www.vso.org.uk/Images/Burden\\_of\\_Care-tcm79-2102](http://www.vso.org.uk/Images/Burden_of_Care-tcm79-2102) (Accessed 12/04/2009).
5. Akintola O. A gendered analysis of the burden of care on family and volunteer caregivers in Uganda and South Africa. Health Economics and HIV/AIDS Research Division, University of KwaZulu-Natal, Durban; 2004.
6. Oluwagbemiga AE. HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State. *Journal of Social Aspects of HIV/AIDS* 2007, Vol. 4(3)
7. Opiyo PA, Yamano T, Jayne TS. HIV/AIDS and home-based care. *International Journal of Equity in Health* 2008;7:8. Available from <http://www.equityhealthj.com/content/7/1/8> (Accessed 25 January 2010).
8. Pakenham KL, Dadds MR. Carers' burden and adjustment to HIV. *AIDS Care* 1995;7(2):189-203.
9. Dwyer JW, Lee GR, Jankowski TB. Reciprocity, elder satisfaction, and caregiver stress and burden: the exchange of aid in the family care giving relationship. *Journal of Marriage and Family* 1994;56(1):35-43.
10. Sisk RJ. Caregiver burden and health promotion. *International Journal of Nursing Studies* 2000;37(1):37-43.
11. O'Neill J, McKinney M. Care for the caregiver. In: O'Neill J, Selwyn P, Schietinger H, eds. HIV/AIDS Bureau, health resources and services administration. Washington, DC: US Department of Health and Human Services; 2003, p.85.
12. Stull DE, Kosloski K, Kercher K. Caregiver burden and generic well-being: opposite sides of the same coin? *The Gerontologist* 1994;34(1):88-94.
13. Lindsey E, Hirshfeld M, Tlou S. Home-based care in Botswana: experience of older women and young girls. *Health Care Women International* 2003;24(6):486-501.
14. Ama NO, Seloilwe ES. Estimating the cost of care giving on caregivers for people living with HIV and AIDS in Botswana: a cross-sectional study. *Journal of the International AIDS Society*;2010. Accepted for publication, April 2010.
15. Pearlín LI, Aneshensel CS, LeBlanc AJ. The forms and mechanisms of stress proliferation: the case of AIDS caregivers. *Journal of Health Soc Behaviour* 1997;38(3):223-36.
16. Brown MA, Powell-Cope GM. Caring for a loved one with AIDS: the experiences of families, lovers and friends. Seattle: University of Washington Press; 1992.
17. Hendrick J. The impact of HIV on caregivers. *Canadian Psychological Association* 2000. Available from [www.cpa.ca/phase/caregivers.pdf](http://www.cpa.ca/phase/caregivers.pdf) (Accessed 15/08/2008).
18. Mugo Fridah W. Sampling in research. Available from <http://www.socialresearchmethods.net/tutorial/Mugo/tutorial.htm> (Accessed 17/06/2010).
19. Creative Research Systems. The Survey Systems – Sample Size Calculator; 2003.
20. World Health Organization. Community home-based care in resource-limited settings: a framework for action. WHO: Geneva, Switzerland; 2002.
21. Sevcik MA, Bradham DD, Winston-Salem NC, Baltimore MD. Economic value of caregiver effort in maintaining long-term ventilator-assisted individuals at home. *Heart and Lung* 1997;26(2):148-57.
22. Keeter S, Kennedy K, Dimock M, et al. Gauging the impact of growing nonresponse on estimates from a national RDD telephone survey. *Public Opinion Quarterly* 2006;70(5):759-79.
23. Visser PS, Krosnick JA, Marquette J, Curtin M. Mail surveys for election forecasting? An evaluation of the Colombia Dispatch Poll. *Public Opinion Quarterly* 1996;60:181-227.