Occupational risks and challenges faced by caregivers of persons living with HIV/AIDS in Kanye community home-based care programme, Botswana

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ABSTRACT

In Botswana, the primary caregivers for people living with HIV/AIDS are informal workers who form part of the health system. The aim of this study was to explore occupational risks and challenges which caregivers in Kanye, Botswana face. This qualitative research was descriptive and exploratory in nature and involved ten focus group discussions with 82 primary caregivers and in-depth interviews with five nurses in the community home-based care programme. Caregivers experienced occupational risks and challenges associated with inadequate provision of care packages and clinical waste handling and disposal, poor support, inadequate involvement in decision-making in the programme, and a lack of training. Recommendations related to these problems are included.

Key words: HIV/AIDS, caregivers, community home-based care, occupational challenges

INTRODUCTION

In Botswana, the primary palliative caregivers for people living with HIV/AIDS and other terminal conditions are informal workers whom the government has entrusted with the responsibility for providing home-based care. They are family or community members.

A register of the caregivers working in an area is kept at each clinic. These people are with the patients on an almost 24-hour basis. They are supposed to be provided with care packages, containing gloves, napkins, bedpans, mackintosh and draw sheets, disposable pads, incontinence sheets, disinfectants, dressing pack and supplementary food for the patient,[1] which they collect from the clinics. In addition, there are community caregivers (commonly called volunteers) who move from house to house to assist the primary caregivers. The caregivers are supervised by nurses from the clinics. Together, they comprise the community home-based care (CHBC) programme, which was formally integrated into the health care system in order to ease congestion in health care facilities, and because of the perceived goodwill and confidence in the caregivers.[1]

Statement of the problem

HIV/AIDS caregivers can be exposed to occupational risks during their care giving tasks.[2] Apart from the risk of infection, the negative impact of HIV/AIDS can result in serious challenges for caregivers, leaving them emotionally, socially, economically and psychologically affected.[3,4,5] These problems contribute to care giving difficulties, as well as causing stress and burnout of the caregivers.[5] A lack of the necessary tools and resources to adequately effect care giving can be a significant challenge. In the context of HIV/AIDS, the caregiver's support system can determine their capacity to deliver care. Good psychosocial support systems can lead to a good working environment and relieve stress and are necessary to alleviate or mitigate the socio-economic, emotional and psychological stresses and challenges inherent with care giving.[4]

Earlier studies in Botswana had identified problems in the CHBC programme with respect to food, care packages and generally poor caring environments.[6,7] Caregivers felt overburdened, exploited, and abused.[8,9,5] These problems were exacerbated by their poverty and usually low educational standards.[10,7] Kelesetse blamed the government for placing too heavy a burden on women caregivers, contending that the process was exploitative, with the government passing its responsibility of caring for the sick onto women caregivers.[11]

In addition, anecdotal complaints from the caregivers and the community at large about the programme operations had been received by the author. During a 2004 evaluation of the contribution of caregivers to the CHBC programme in Kanye, Botswana caregivers had reported that the contents of care packages were inadequate and the supply was unreliable.[12] This was a concern as without money to buy materials such as gloves, caregivers would likely wash clients and handle contaminated articles with their bare hands thereby exposing them to the occupational risks of infection with HIV and other pathogens.[13]

With these concerns in mind, a study to specifically investigate the occupational risks and challenges faced by the caregivers was conducted between 2005 and 2006. The rationale for the study was to determine whether the situation had changed and if not, to suggest solutions to the problem. The study is important since caregivers provide CBHC in many developing countries and form a large part of the informal sector. Its findings could be useful for similar situations.

RESEARCH METHODOLOGY

Research setting

The research was conducted in Kanye village, in the Southern District of Botswana, which had a population of over 40 000 in 2001.[14] The Southern District HIV prevalence rate was 25.8% according to 2003 national HIV/AIDS statistics.[15] There were five clinics, two health posts and a large Seventh Day Adventist referral hospital. Each clinic had a register of CHBC programme caregivers. Although the Kanye CHBC programme was regarded as performing well by government standards, it was experiencing a high death toll among the patients.

Research design

A qualitative design was used in this descriptive and exploratory study as it sought to understand the meaning and experience of the participants working as caregivers.[16] In addition, quantitative component was used to determine the demographic profile of the caregivers. The primary caregiver, therefore, formed the unit of analysis.[16]

> ***". . . the primary palliative caregivers for people living with HIV/AIDS and other terminal conditions are informal workers"***

Data collection

Two interview guides were used. The first was to guide focus group discussions (FGDs) with the caregivers. The second was for individual in-depth interviews with nurses, to compare, corroborate and contrast the data obtained from the caregivers. The caregivers guide contained a demographic profile section to collect data on age, gender, education and economic activity. Both the guides contained open-ended questions in order to stimulate discussion regarding the occupational risks and challenges experienced by the caregivers. The tools were refined following a pilot study with five caregivers and one nurse.

The FGDs were facilitated by the researcher and two research assistants. Whilst one research assistant held the microphone near the participant, the other was making notes and all noted the participants' non-verbal behaviour. The FGDs and interviews lasted between 60 minutes and 90 minutes.

Sampling strategy

All 140 primary caregivers listed in the CHBC register were selected for study inclusion, but only 82 (59%) actually participated. This convenience sample was formed into ten groups of six to twelve caregivers based on the number registered at the clinics. For some clinics, such as Kgwatlheng and Kanye Main clinic there was more than one group, while the two health posts of Sebego and Dilolwe had only one FGD. The size of the groups ranged from six to twelve caregivers. All five nurses who supervised the caregivers were interviewed by the researcher.

Ethical and legal requirements

The study followed all the legal and ethical protocols. Approval for the study was granted by the Human Research and Development Committee Board of the Ministry of Health. Permission to collect data was then obtained from the Southern District Council. All participants gave written consent, having been informed of their rights and freedom to withdraw voluntarily if they wished to do so or if they felt uncomfortable with research proceedings.[16]

Data analysis

The analysis took the form of content analysis. The audio taped data was transcribed, sorted according to codes and grouped into themes and sub themes.

Trustworthiness and credibility

To reduce bias, there was double translation of the instruments, namely translation from English to Setswana and then from Setswana to English by two independent translators with the two parties coming together to reach agreement on the final wording. Data from the caregivers was corroborated by that of the nurses.

FINDINGS

Demographics of the caregivers

Forty-six (56%) were aged between 50 and 59 years and 28 (34%) were 60 years and older. Regarding education, 29 (35%) had never been to school; 32 (39%) had only primary education, 17 (21%) had secondary education and only 5% had tertiary education. On the economic front, the majority admitted to living in poverty. Seventy-two (88%) had no income to support themselves. On gender, 80 (98%) were women and only two (2%) men.

Occupational risks and challenges

Inadequate provision of care package

Over half the participants confirmed that the care packages offered by the clinics to the caregivers were inadequate as they did not contain all the necessary tools. They indicated that this was the most serious problem causing a progressive decline in the quality of care in the Kanye programme. There were shortages of gloves and napkins in particular. Almost half of the government recommended care package components were not available at the clinics at the time of research. Because of the poverty of the caregivers, many could not buy them and had to do without or try to recycle them. This posed both hygiene and clinical challenges. The following quotes testify to the insufficiency of the care packages:

> "The necessities to help the sick are no longer there. We are not helped well."
>
> "We are all going to die from contagion. We do not know our status."
>
> "The care package components are not adequate. Sometimes there is nothing."

Ineffectiveness in handling and disposal of clinical waste

Clinical waste was supposed to be taken to the clinics for transport to Jwaneng or Lobatse for safe disposal. More than half of the caregivers admitted that handling and disposal of clinical waste was a big challenge. This was because most lacked transport and therefore had to walk to the clinics. The elderly especially faced serious transport problems as it was not possible to use public transport to ferry the waste. Family members, especially the young, refused to help, which meant that the caregivers had the extra burden besides care giving of having to take the clinical waste to the clinics.

Poverty of the caregivers and inadequate nutrition

The most common problem experienced was the lack of food for their patients as the food baskets were inadequate. Because of their own poverty, caregivers conceded they were not able to provide what their patients desired. This was exacerbated by inadequate support from relatives, friends or community systems and a lack of understanding by patients, which was stressful for them. The following sentiments were echoed by many caregivers in all the FGDs.

> "The 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."
>
> "We are poor and have nothing else to do except care giving."

Weak community support system

Caregivers were inadequately assisted by relatives, friends, neighbours, private individuals, grassroots traditional and political leaders and other service delivery networks like the NGOs and CBOs. The sentiment below was typical:

> "Relatives and family members help here and there, but very little."

Demonstrating the pain and agony a caregiver undergoes while left to carry out care giving alone, an 18-year-old female caregiver broke into tears explaining how all her brothers and sisters left her alone taking care of her ailing father.

> "I cannot get time to go and look for a job as I'm left alone at home caring for my father. They all (brothers and sisters) went for good leaving me to struggle with care giving."

This lack of support can result in caregivers being overwhelmed, making the coping process difficult.

Inadequate supervision and counselling by health care personnel

Disappointment as far as visiting, counselling and supervision from the health care personnel such as nurses, counsellors, social workers and doctors was extremely common. There was a lack of guidance, direction and motivation, which had a negative effect on care giving productivity and coping in general. The following sentiments were expressed:

> "The health personnel do not come to supervise us."
>
> "The health personnel only counsel and visit a few people. We use our natural instincts to do care giving."
>
> "We do not see the health personnel coming to encourage us. We rarely get their help."
>
> "We do not get counsellors to offer counselling in our caring duties."

Caregivers reported that they preferred health workers to visit the households to supervise and counsel them, and encourage the patients to take their drugs. Such visits would improve the contribution to care giving and enhance their coping process.

Inadequate support from the social workers

Virtually all the participants were dissatisfied with the social workers' services. They associated the inadequacies of the food basket with the ineffectiveness of the social workers because of delays in their assessments for food baskets.

Inadequate motivation and incentives

Half of them felt the programme was de-motivating, demoralising, lacking in incentives, recognition, rewards or any strategy to motivate the caregivers, which made coping immensely challenging. Lack of incentives was the reason why care giving does not attract young women and men. Incentives could include stipends, bonuses, encouraging words, food packages, toiletries, supervisory visits, relieving somebody before s/he gets overwhelmed and having caregivers work in shifts. The lack of psychosocial support like counselling, social support from relatives and the community in general, and inadequate care package were commonly regarded as factors responsible for poor motivation and reduced care productivity.

Caregivers not involved in the decisions about running the programme

There was general consensus that caregivers were excluded from decision-making involving the running of the programme. Caregivers indicated that decisions were taken at management level without consulting them and yet they are the backbone of the programme. This they considered as lack of recognition for their efforts. They also expressed concern that they are not consulted or involved in making the care plan and care package.

Training of the caregivers

Most indicated that they had not been trained in care giving and hence used their natural intuitive knowledge. Participants from many FGDs echoed the following sentiment:

> "We do care giving through God's wisdom and grace."

Some caregivers indicated fear that they would contract their patients' diseases as they knew little about care giving. The situation, they worried, was exacerbated by lack of care package components like napkins.

> "We are all going to die from contagion. We do not even know our status."

Lack of education compounded the problems. Most of the low literacy level caregivers (who were also elderly) had problems with following the medical and hygiene protocols and understanding disease progression in their patients. Only a few caregivers reported having been given a few days' training workshop some years back, and a few had received demonstrations from the CHBC nurses on such issues as house hygiene and nutrition, how to bath a patient and how to keep one's client happy.

DISCUSSION OF THE FINDINGS

Kanye caregivers were found to be of low economic status, low education and predominantly women. This is similar to other studies – 33% of caregivers in Maun and Kweneng had lower primary education,[17] all but one were women in Tutume, Botswana and in Molepolole, Botswana, all were women.[18] This supports the allegation that care giving duties have been left to women, sometimes leaving them overwhelmed, which amounts to gender exploitation.[11] Most were over 60 years of age, and it is possible that they may not have been physically strong enough to withstand the care giving demands, making coping difficult.

They faced serious biological hazards associated with the managing, handling and disposal of clinical waste, primarily due to inadequate care package materials, lack of transport and lack of assistance.[13] The lack of protective equipment such as gloves and materials like incontinence pads and bandages placed them at risk of infection and posing environmental and clinical challenges.[13] Mokgwaru in his study on clinical waste in Botswana found that most CHBC programmmes handled and disposed of the clinical waste in an unprofessional manner.[2]

A lack of social and psychological support resulting in a poor working environment was a common problem. The importance

> “Kanye caregivers were . . . of low economic status, low education and predominantly women.”

of providing caregivers with incentives and financial assistance of some kind has been emphasised and addressed in other countries.[4] In Namibia, for example, caregivers are given bonuses and a little money to support their living, while The Aids Service Organization caregivers in Uganda are paid more than other Government workers of their calibre. In line with the study by Jacques and Stegling[6] caregivers were not volunteering because of the love and inherent spirit of volunteerism, but because of the desperation emanating from the fact that they did not have any job or piece job, and due to assumed assistance that their volunteerism may bring in the future.

Caregivers complained about inadequate involvement in decision-making. Involving the caregivers and their patients in developing a care plan is very important as it strengthens care ownership, makes the patient cooperative and so reduces caregiver/patient conflict in the care process.[19] Kanye caregivers received little training to aid their effectiveness and educate them about protection from occupational risks. Not training caregivers has been likened to sending them into a minefield to get hurt.[4] Uys and Cameron[19] assert that “no matter what their background, caregivers should not be sent to do home visits before they have a good basic training and understand the physical, spiritual, psychosocial, and emotional condition they may encounter, and how to deal with these challenges” (p.117).

STUDY LIMITATIONS

The community volunteers who assist the primary caregivers in care giving, the community leaders and other local policy makers were not interviewed. It is possible that their perceptions could have assisted with data triangulation. One of the reasons that only 59% of the targeted caregiver population participated may have been that the study was conducted over the holiday period.

LESSONS LEARNED

Informal caregivers are exposed to serious biological hazards associated with the managing, handling and disposal of clinical waste.

They are part of the health care system, assisting by easing congestion in health care facilities and should have adequate support systems.

They need adequate care giving tools, supervision from health care professionals, rewards and incentives, and counselling service support.

CONCLUSIONS AND RECOMMENDATIONS

The study found that the biological, emotional, social, economic and psychological challenges identified in other earlier studies were serious and widespread amongst the Kanye caregivers. They experienced inadequate support systems due to a lack of care giving tools, poverty, inadequate supervision from health care professionals, a lack of motivation, unsatisfactory service from the social workers, and inadequate counselling service support. These occupational challenges should be addressed if care giving effectiveness and efficiency is to be achieved without adversely affecting the health of caregivers. The important role of caregivers as a component of the health care system should be recognised.

Recommendations include the adequate provision of care giving packages; clinical waste collection services; adequate training and supervision from health service providers; instituting rewards, recognition and incentives to raise the morale and motivation of the caregivers; increasing the number and services of social workers; and improving counselling services for the caregivers. In addition, care programmes for caregivers should support coping mechanisms such as the inclusion of respite provisions to reduce stress and prevent burnout.

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