

Validating that palliative care giving is a stressful occupation: the case of the Kanye community home-based care programme, Botswana

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Abstract

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Background: It remains an incontrovertible fact that the phenomenon of HIV/AIDS has not only posed major health and development challenges, but is also a stressor experienced at local, regional and global levels. This article explores the stress-related challenges facing volunteer palliative caregivers in the Kanye community home-based care (CHBC) programme.

Methods: The study was explorative in nature and qualitative in design, and used convenience sampling methodologies to involve 82 registered primary caregivers and the five CHBC nurses in the programme as research participants. Participant observation was also used.

Results: The study found the following aspects inherent in care giving to be immensely stressful and challenging:

- Heavy caseload of the caregivers;
- Ageing of the caregivers;
- Stigma and discrimination abound in care giving;
- Conflict between caregivers and clients;
- Poor state of referral networks;
- Inadequate care packages;
- Poverty of the caregivers themselves; and
- Inadequate food, psychological support and community support networks.

Conclusion: The study recommends that putting in place a favourable working atmosphere and environment to address the stresses and stressors of care giving would be pivotal to improve this occupation.

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Aims and objectives

The study aimed to explore the phenomenon of stress associated with palliative care giving of people living with HIV/AIDS.

Operational definitions

Palliative caregivers refers to family and community caregivers who stay with CHBC clients (HIV/AIDS and other chronically ill persons) to offer palliative care.

Palliative care is the care that is carried out not to heal, but to relieve pain, distress, psychological loss, feelings of worthlessness and anxiety, and that gives hope, dignity, esteem, happiness and inculcates the feeling in the sick person that all will be well.

Introduction and background

Stress is the reaction to events, environmental or internal, that tax or exceed a person's resources, whether these

are physical, social, perceptive or psychological. As human beings are naturally endowed with coping capacities and resources, stress usually results when these are overburdened.¹ According to Fineman,² stress is a psychological state of high anxiety reflected in self-description, such as being very unhappy, fearful, overwhelmed, and sometimes socially withdrawn. This state may be accompanied by physical symptoms, gastric upsets and ulcers, headaches, migraines, back pains, high blood pressure and heart diseases. Stress usually results from people's inability to cope with threatening problems or difficulties, or because of failing to remove the threat or the stressor. If not checked, or if adaptations to absorb stress are not found, stress can develop into a condition called burnout. Burnout is a state of emotional and physical exhaustion characterised by a lack of concern for the job, low trust of others, depersonalisation of clients, loss of caring and cynicism towards others, self-depreciation, low morale and a deeper sense of failure. It breeds disillusionment and apathy.³

It is worth noting that stress also has positive aspects. People under stress work harder and are able to achieve greater tasks than they would have if left to achieve the tasks at their normal pace. Stress can fuel creativity, create excitement, or energise an individual for an important event or project. Stress lends excitement and vigour to many aspects of life. It is only when stress becomes unmanageable and gets out of control that it can wreak havoc upon one's body, peace of mind, and productivity.¹

Today, HIV/AIDS represents a stressful phenomenon to all institutions, with the health sector being worst hit. The current increase of the population-based prevalence to 17.6% (as indicated by BAIS III results) in Botswana from 17.1% in 2004 (according to the BAIS II results)^{4,5} provides an indication of how the government, non-governmental organisations (NGOs) and civil society generally could be stressed by the phenomenon, especially after the current successful national rollout of antiretroviral drugs (ARVs). As a response to mitigate the effects of HIV/AIDS, the government has, for instance, institutionalised community home-based care programmes to complement and supplement the services of its health sector.⁶ Due to an unfavourable care-giving environment, for example the lack of an organised training schedule or plan, coupled with inadequate supervision in the Kanye care programme, the caregivers of people living with HIV and AIDS in Botswana, just as in many other settings in the world, usually succumb to different aspects of physical, social, emotional and psychological stress. This is due to the conditions inherent to their caring environments, although circumstances and the magnitude or strength of the stressors are circumstantial and vary from place to place. The social issues and circumstances surrounding HIV/AIDS have made working to assist HIV/AIDS clients a difficult task. Stigma is such a factor, which, although perceived to be progressively decreasing in Botswana, still poses a daunting challenge to care giving.⁷

While caregivers in most settings in Botswana, and in many African countries, generally have been motivated and encouraged by the blood relations and attachments between them and their clients, or what Kang'ethe in his study in Kanye called the "blood is thicker than water paradigm" (*Kang'ethe paradigm*),⁷ many caregivers suffer considerable poverty constraints, sometimes lacking even transport to take their clients to the referral hospital for a check-up or review. In some settings, caregivers report being asked for food by their clients, while they themselves are hungry,⁸ and this sets forth a wave of social stress and distress.

Methods and settings

Research design

Qualitative design was used in this case study. According to Rubin and Babbie,⁹ a qualitative research design is inductive in that the researcher builds abstractions,

concepts and theories from the details from the field, and involves fieldwork whereby the researcher is the primary instrument for data collection and analysis. This design is justifiable because the study sought to explore the thinking, feelings and attitudes of the caregivers concerning their contribution to care giving, and to explore the state of stress and distresses that abound in care giving. This design is appropriate for the study as it facilitates the understanding of the process, in this context the process of care giving, rather than of the outcomes. Participant observation was also used to capture the mood and temperaments of the caregivers.

Research instruments

Two slightly different interview guides were used to steer 10 focus group discussions (FGDs) with the caregiver participants, and one-on-one interviews with the five CHBC nurses. The interview guides had a profile section that required the research participants to provide their profile data, such as age, literacy level and gender. All the other questions in the interview guides were open-ended questions and served the purpose of guiding the discussions. The instruments had been tested and refined during the pilot study. Nurses formed the caregivers' supervision team.

Sample selection criteria and procedure

The study used convenience sampling to select all 140 registered primary caregivers as they appeared in the Kanye CHBC register. Eighty-two (59%) registered primary caregivers, making up 10 focus group discussions, turned up for the focus groups. The size of the groups ranged from six to 12. All the focus group discussion (FGD) sessions lasted between 60 minutes and 90 minutes. However, the researcher stopped them when saturation point was reached. Each participant was involved only once in a FGD. The author chose to have only one session per day in order to adequately arrange the sessions and to ensure that the members constituting the session in the following day were adequately prepared, located and alerted. The CHBC register in each clinic helped to identify the number of the primary caregivers served by each clinic and, hence, made the sample grouping for the FGD easier. The community caregivers (referred to as volunteers in the Botswana context) also helped to clarify the number of primary caregivers they were supervising and supporting in their care-giving roles. This eased the logistical process of arranging the focus groups.

Also, all four CHBC nurses and their coordinator were selected using convenience sampling procedures. They were selected because of their mandate of supervising the CHBC programme and the caregivers. The primary caregiver, therefore, formed the unit of analysis.⁹ The selection criteria and grouping of the caregivers disregarded age and gender and was based on the geographic location and proximity of

the caregiver to the clinic/health post where the caregiver collected the tools of his/her client. Some clinics constituted more than one focus group. The caregiver participants were collected from the following clinics: Kgwatlheng, Kanye Main, Mafhikana, Dada, and Mmamokhasi; and from the Dilolwe and Sebogo health posts, and were taken to the Miracle Family Christian Centre (MFCC) premises, where the focus group discussions were held. However, the CHBC nurses were each interviewed at their place of work. Among the strategies for collecting data were the jotting down of notes, probing, questioning and audio-taping information from the respondents.

Ethical and legal requirements

To ground the study in an ethical and legal environment, all appropriate legal and ethical issues were taken into consideration, holding debriefings with the caregivers and nurses to explain the study goals and objectives and the whole research process in general. Those who agreed to become involved in the study signed consent forms. The researcher promised to maintain confidentiality and anonymity of the data collected, and to use no coercion during the discussions. The respondents could withdraw from the research voluntarily.⁹ The researcher complied with all the research permit application procedures in relation to the Human Research and Development Committee Board (HRDC), and was issued with a research permit for the study. The researcher then had to write a letter to the Southern District Council asking for authority to enter into the field to collect data, which was granted.

Data analysis, interpretation and bias reduction

To carry out the data analysis, the information from both the focus group discussions with the primary caregivers and the one-on-one interviews with the nurses was taped and then transcribed. The crude data were sorted, rearranged and reduced to manageable categories and themes using a coding process. Quotes, words, analogies and jotted notes were used to inform data collection, while tables and graphs were used to present the data and therefore the findings. This formed the basis of analysis and gave themes such as stressful occupation; clinical waste challenge in care giving; inadequate NGO support for care giving; incentives and motivation and traditional healers and care giving. The results from the pilot study, involving five caregivers and one nurse, that preceded the study served to remove ambiguities in the instruments and helped to focus the study. This contributed to a reduction in study bias and an improvement in data reliability and validity. Double translation of the instruments, i.e. translation from English to Setswana and then from Setswana to English by two independent translators, with the two parties coming together to settle on the differences, was also done and served to clean up the instruments and increase their focus, and therefore increase data reliability and validity. This also helped to reduce data and result bias.

To further strengthen data reliability and validity, the two interview guides or instruments that were used differed only slightly, and the two sets of responses were confirmed and cross-checked with each other.

Research domain

The research was carried out in Kanye village, one of the largest and oldest villages of the Bangweketse tribe. The village has close to 50 000 inhabitants according to the Central Statistics Office (CSO),¹⁰ and was well served with adequate health facilities. It has a big Seventh Day Adventist (SDA) hospital, which is used as a district referral hospital, five clinics and two health posts. A clinic, by definition, is bigger in terms of the size of human resources and facilities and serves a bigger population than a health post. The researcher was prompted to carry out the research, as the programme was experiencing a high death toll and a high HIV prevalence rate of 25.8%.¹¹

Findings

Demographics

Age was found to be a crucial factor affecting care giving, with 46 caregivers (56%) being 50 years and older, and 28 caregivers (34%) being 60 years and older. The study revealed, through participant observation, that most of the caregivers were women and also that they were physically not strong enough to withstand the care-giving demands and dynamism, especially those over 60 years of age, and that they were apparently stressed, making coping difficult. Regarding literacy level, 29 caregivers (35%) had never been to school, 32 (39%) had only primary education, while 17 (21%) had secondary education. Only 5% of the caregivers had a tertiary education. The caregivers indicated that their low literacy level was behind their low coping capability and low quality of care. It was also a source of stress, as those with low literacy levels could not easily understand the intricacies of care giving.

On the economic front, many of the caregivers indicated they were stressed by poverty. Seventy-two of the caregivers (88%) had no income to support their clients and themselves. They indicated that poverty was the greatest stumbling block besetting the care-giving process. Regarding gender, the data indicated that the programme faced a seriously skewed gender dimension, with 80 of the caregivers (98%) being women, and only two (2%) being men. According to the caregivers, the communities had thrown the weight of care giving to them, and this presented an overwhelming experience in the era of HIV/AIDS.

Heavy caseload stressful

Close to three-quarters of the study participants indicated that care giving was a stressful occupation because most of them were taking care of more than one client. The statistics

indicated that 30 caregivers (36%) took care of more than two clients; 20 caregivers (24%) took care of two clients; four (5%) caregivers had three clients; while six caregivers (7%) took care of more than three clients. However, the 52 caregivers (63%) taking care of only one client anticipated that their case load was not as heavy and that, other factors being constant and favourable, they were supposed to take good care of their clients. This could partly explain the sustainability of the Kanye programme. However, the caregivers regretted that, even for those whose caseload was not heavy, the environment they worked in, such as the lack of food and care-giving facilities, made care giving equally distressing and stressful, with caregivers with a relatively lighter load facing almost the same challenge as those who had many clients. The caregivers made the following comments on caseload:

"This job of taking care of many clients is too difficult for most of us."

"Lack of care facilities has exacerbated the challenge of care giving."

Therefore, several factors interplayed to make care giving a heavy duty and a stressful occupation.

Ageing of the caregiver

Nearly all the caregivers indicated that age and ageing presented stress and distress to care giving, making care giving a very difficult occupation. Twenty-eight caregivers (34%) were 60 years and older, 17 (21%) were between 60 and 69 years old, while 10 (12%) were between 70 and 79 years old. The oldest caregiver was 85. From the observations of the researcher and his research assistants, the elderly caregivers appeared too weak and demoralised to withstand the care-giving demands and dynamism. The caregivers indicated that ageing made it difficult for some of them, especially the elderly, to understand the dynamism of sickness, as they sometimes did not know if the clients were getting worse and that it was time for referral. They also added that the ageing challenge was exacerbated by poverty, which made care giving a stressful occupation. They had the following sentiments on ageing and its relationship to care giving:

"Some of us are old and we need to be assisted with all the needs of our clients."

"We are old. Sometimes we get confused. We do not know the results of our caring. We lack adequate knowledge on care."

Stigma and discrimination in care giving

Although close to half of the Kanye research participants appreciated the fact that stigma and discrimination were dwindling in the Kanye region, they indicated that stigma still presented a daunting challenge, making care giving a

stressful occupation. The caregivers reported that, because of stigma and discrimination, some of them who had HIV/AIDS clients did not want to admit the truth and therefore did not seek medical and social assistance in time. This led to all the avenues of any possible assistance nearby being closed, with some preferring to go for assistance far away from the client's village. This, the caregivers admitted, was expensive and unfair to the clients, as the clients missed medication and treatment if they did not have money to travel far. This posed a serious medical challenge. Some caregivers pointed out that it was due to stigma that some caregivers and their clients sought assistance from traditional healers, who have been proven not to handle HIV/AIDS complexities successfully.¹² Caregivers made the following comments on the impact of stigma on care giving:

"Due to stigma, some caregivers and their clients go to seek medication and assistance far away, where they are not known."

"Stigma is bad. It makes people not seek medication and assistance in time."

"Stigma makes many caregivers and their clients shun the clinics and clandestinely visit the traditional healers."

Poor state of referral networks

The research findings confirmed that the majority of the Kanye caregivers reported being subjected to a poor referral system, throwing them into a state of stress and confusion. The caregivers reported that the Kanye SDA referral hospital did not have adequate human resources, so that caregivers who took their clients to the hospital usually collected them back unattended, sometimes after having waited for the service the whole day. Most appointments with doctors usually were unsuccessful. The traditional hospital role of washing and feeding the patients took a different route, as it was the caregivers who had to feed and wash them during the period of hospitalisation. The caregivers also reported fearing or risking contagion, as they were not given any protective clothing. They also lamented the lack of care-giving tools in the clinics and the referral hospital, which made care giving very stressful. Inter-clinic referral and communication were also not good. This, the caregivers reported, resulted in some clinics having certain items in excess which would be in insufficient supply in the neighbouring clinics. The following sentiments pertaining to the referral system were captured in the focus group discussions:

"Caregivers and their clients are not treated well in the Kanye SDA hospital."

"Appointments in the Kanye SDA referral hospital usually fail."

"It is the caregivers who go to wash and feed their clients at Kanye SDA hospital."

"Caregivers are not given any protective clothing to attend to their clients, while hospital workers use them."

Conflict between clients and caregivers

About a third of the Kanye respondents reported cases of constant conflict between them and their clients. This they attributed to their inability to adequately provide for their clients due to their poverty. The caregivers reported that their clients were unhappy with them, as most did not understand the situation well. A large number of caregivers reported that their clients could not take in any of the available food and that, if given "motogo" (the ordinary Motswana staple porridge), they either refused it or vomited it up, throwing the caregiver into further confusion, anger and desperation, as money to buy the special food for the clients may not be forthcoming. The following quote had unanimous support.

"The client wants good food, you give him/her motogo (thick sorghum porridge and a common staple food for an ordinary Motswana), she/he vomits."

Poverty of the caregivers and inadequate food

The majority of the Kanye caregivers confirmed they were poor and did not engage in economic activities to support themselves economically. Seventy-two caregivers (88%) had no economic engagements to make a living, while only ten (12%) had some paying occupation. The most common problem and stressor quoted by almost all the participants in the different focus group discussions was a lack of adequate and necessary nutrition for the client. The caregivers reported that not all of them were receiving the food basket, with the social workers who assessed the food basket requirement of the clients taking too long to do their work. Even for those who received the food basket, the food components were not adequate; sometimes some food items were overrepresented, while others were underrepresented, and sometimes the food basket contained stale food items. Because of their poverty, the caregivers conceded they were not able to provide what the client desired. This was also fuelled by a lack of support from relatives, friends or community systems. A number of participants commented the following:

"We are poor and have nothing to provide to our clients."

"Food basket is inadequate and does not meet the needs of the clients."

"This food most of the time is not useful to the client. The food basket is standardised for all the clients, yet the ailments are different."

"Some food items are not there in the food basket supplier shop and our sick clients and ourselves are suffering. We need help."

"It is not all the sick clients who get food baskets. Some of us have been waiting for the assessment results of the social workers for a long time."

Inadequate care package

Forty-one respondents (50%) in the Kanye study lamented that they were stressed and demoralised because of the inadequacy, unavailability and unreliability of care package facilities in the clinics. They confirmed that the care package offered by the clinics to the caregivers was inadequate, as it did not contain all the necessary tools needed for care giving. As a result, the caregivers were sometimes forced to buy components of the care package, such as napkins or gloves, or do without them. Because of the poverty of many caregivers, most were not able to buy these items and had to recycle them or do without them altogether. The following testifies to the insufficiency of the care package:

"These days, there is nothing in the clinics. The caregivers are suffering."

"The necessities to help the sick are no longer there. We are not helped adequately."

"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."

Since the care package forms the support skeleton for the caregivers, inadequate provision of it implies that the caregiving process suffers because of the resultant compromise.

Inadequate psychological support

Close to three-quarters of the caregivers confirmed that they had not been given adequate psychological support in the form of counselling. They attributed their low quality of care giving to a lack of counselling and other support necessary to bolster care giving. They made the following sentiments about psychological support:

"We do not get counsellors to offer us counselling on our caring duties."

"We do not see the health personnel coming to encourage us. We rarely get counselling."

Inadequate community support networks

The empirical findings confirmed that the majority of the caregivers were rarely assisted by relatives, friends, neighbours, private individuals, grassroots traditional or political leaders, or by other service delivery networks like NGOs and community based organisations (CBOs) making it a very stressful undertaking for the caregivers. The following sentiments were recorded:

"Care giving has not benefited much from NGOs, CBOs, private organisations and private individuals."

“Most of our local leaders only get involved when we are holding funerals.”

“Some community members do not support care giving. Some stigmatise our clients and ourselves.”

“Relatives and family members help only a little.”

Discussion of the findings

The Kanye care programme was found challenged by a predominance of women, their age and ageing process, and their low literacy levels. Atta and Fidzani indicate that over 50% of caregivers in most of the Botswana CHBC programmes are old women who may not be able to follow the guidelines of the care process adequately.¹³ Of the 83 community caregivers in Kang'ethe's 2004 study in Kanye, only two were men.¹⁴ It would seem that care-giving responsibilities in Botswana, as in many other developing countries, fall into the hands of elderly women and grandparents, who need a lot of psychological nourishment to meet their coping challenges.¹⁵ According to Uys and Cameron¹⁶ and the Nurses Association of Botswana,¹⁷ counselling debriefings help restore confidence and strength to a caregiver so that she/he can continue working in a stressful environment successfully. Counselling restores one's emotional and psychological wellbeing and therefore normalises living. To save the elderly caregivers from immense stress, the programme needs to have attractive incentive packages to attract people who are relatively younger to care-giving duties.

The Kanye caregivers faced the challenge of low literacy levels. This meant that following the disease protocol adequately was a challenge. The Kanye caregivers had the same low educational status as the Maun caregivers in the study by Phorano, Ngwenya and Nthomang.¹⁸ Since the Kanye programme did not have an organised training programme, this presented a daunting and stressful challenge. Atta and Fidzani highlighted similar findings in their research on care giving that found that elderly women caregivers faced the challenge of following the disease progression of their clients.¹³ It is recommended that the Kanye care programme institutes on-the-job training in an endeavour to sharpen the general skills of the caregivers.

The prevalence of poverty among the Kanye caregivers matches the findings of a study in Kweneng, which found poverty to be a big challenge to care giving, with the lack of food being the gravest challenge.¹⁹ This is reinforced by Kang'ethe's study in 2004, which found HIV/AIDS to be a poverty-friendly disease.¹⁴ This is because the participants confirmed that most homes where HIV/AIDS struck were increasingly becoming engulfed by poverty. Stress was also a common occurrence.

More than one-third (36%) of the Kanye caregivers took care of more than one client. A heavy workload in any working

institutional setting is bound to cause stress in the worker, and this is one of the reasons for the low quality of care in most care programmes in Botswana, as in many other care contexts in different countries.¹⁴ On the same note, a health care trainer in Kenya describes an elderly woman raising 10 children of her late brother and sister, along with six of her own. The challenge is enormous for an elderly woman like her, with an unbelievably overwhelming burden that leads to even lower quality of care giving.²⁰ It is recommended that such a load be co-shared by other household members in particular, as it can otherwise lead to stress and burnout, overload fatigue and non-performance. Care authorities should have a policy to ensure that no caregiver takes care of more than one client. Advocacy for community networks to reduce the load of a caregiver with more than one client needs be strengthened. Having relatively younger persons assisting in care giving could be a relief, as they would be stronger, resilient and possibly could cope more easily with care giving.

The quality of care giving in Kanye was found to be influenced negatively by the ageing of the caregivers. Ageing represents a normal biological life process impacting on the physical, physiological, psychological and social processes of a person, and is an inevitable and inescapable process in the life of a human being. Inevitably, the change towards senility is marked by a decline in cognitive, emotional and physical energies, affecting productivity overall.²¹ Studies have shown that, as regards problem solving, older adults, especially those over 70 years, fair less well than relatively younger adults.²² Since care giving appears to be an occupation of the elderly in many African country settings, it has been a very stressful undertaking due to their dwindling energy associated with ageing. This explains why some care programmes in Botswana experience low quality care and a high death toll.^{6,7,14} Generally, senility has a bearing on:

- Inability to cope well, especially where physical strength is important to handle a bedridden client,
- Lack of emotional strength necessary to handle the sick clients.

This makes care giving a stressful undertaking.

Several studies have found ageing to largely compromise the quality of care. Studies from Zimbabwe show that, at the age of 80, Ndanda Ncube stressfully wakes up to do the household chores and gather some firewood to feed her six grandchildren,²³ while, in Kweneng, Botswana, Jacques and Stegling found three clients with caregivers who were not able to discharge their roles due to old age or disability.²⁴ If the care giving is to be left to the elderly only, then the traditional safety nets providing for care giving could be stretched beyond their capacity, with resultant inadequate productivity.²⁵ Because of the state of care getting out of hand due to the advanced age of most caregivers, Stephen

Lewis (a UN envoy) advocates for the “grandmother phenomenon”, in terms of which grandparents care for their grandchildren by providing an adult figure, while the children reciprocate by caring for the grandparents, whose caring capacity is seriously compromised by age.²³ There is a need for a paradigm shift in the norms, values and thinking that have placed the burden of care giving on elderly women, as elderly people face a lot of health problems associated with ageing and, therefore, get stressed easily.

Stigma emanating from HIV/AIDS continues to pose a global challenge.²⁶ In a study by Khan and Stegling in Kweneng, all the HIV/AIDS clients they interviewed, in cohort with their caregivers, denied being HIV-positive.²⁷ This means that they failed to utilise welfare services, like the food basket, because of the stigma attached to the programmes. In contrast, and to the relief of the HIV/AIDS campaign, the Kanye caregivers provided the welcome news that stigma and discrimination were dwindling over time. According to Atta and Fidzani, the stigma associated with AIDS isolates the fragile family unit as they try to cope with an HIV-infected family member,¹³ while Festus Mogae, the former president of Botswana, indicated that stigma and discrimination were the biggest stumbling blocks besetting prevention and care initiatives.²⁸ In Maokane village in the Southern District of Botswana, for instance, HIV/AIDS clients were reportedly refusing the vegetables given to them to supplement their food, due to the stigma attached to the help system. This put the caregivers who were responsible for feeding the HIV/AIDS clients in very stressful position.²⁹ It is, therefore, recommended that government, civil society bodies in the care-giving field and private organisations strengthen anti-stigma educational programmes. They should use all public forums to disseminate anti-stigma messages.

The Kanye respondents confirmed that their care giving was beset adversely by the poor referral system and communication. In Botswana, the problem of the poor referral network is generally attributed to understaffing in health care facilities/centres, leading to a constrained care-giving process. This makes it difficult to provide care and support to the caregivers.¹⁷ According to Atta and Fidzani, 95% of the caregivers they studied in Botswana indicated lack of support from health workers, while 58% of the patients reported that they had not been visited by any health worker for a long time.¹³ This meant that their referral challenges were not met timeously. However, the Kanye caregivers would prefer health workers to visit their households in order to supervise them, teach them and encourage the patients to take their drugs. Such visits would improve the contribution of caregivers.⁷

Kang'ethe's study in Kanye found that the referral process and communication between the clinics, and between clinics and the referral hospital, were seriously challenged by administrative, coordination and human resource gaps,

and also that there was a lack of care package facilities.³⁰ Joy Phumaphi, former Botswana Minister of Health (1999–2002), was reported as complaining that, instead of family welfare educators being in the homes advising and helping the caregivers, they only stayed in the clinics, usually to assist the nurses due to understaffing.³¹ According to Uys and Cameron, supervisors should be professional people with good communication skills; have the ability to commit the necessary time to the caregivers (approximately an hour per caregiver every two weeks); have experience and an interest in facilitation, mentoring, and counselling; and have access to psychosocial support themselves.¹⁶ Their core role should be to nurture and mentor the caregivers, and to identify and address problem areas. This would ensure that referral was done timeously, so that the quality of care would be enhanced. In the Kanye CHBC programme, the process of supervising the caregivers is inadequate. The care authorities, in liaison with the government, need to ensure smooth referral flow between and among the clinics, and between the clinics and the referral hospital in Kanye, and in Botswana generally.⁷

Under normal circumstances, inadequacy and competition for resources are known to cause conflict. The inadequacy of the food basket (for those who were receiving it) in the Kanye programme created conflict between the caregivers and the clients, as the latter did not appear to adequately understand the problem and the struggle the caregiver went through to make ends meet. In a study conducted by Atta and Fidzani, 15% of the caregivers indicated that their clients were uncooperative,¹³ while Dant and Gully, in their study in Britain, found examples of elderly clients who were not ready to accept their own vulnerability and who were not able to cope with the erratic timetabling of the services ostensibly meant to help them.³² This conflict emanated from the fact that the client was not considered or consulted during the process of service provision, making him/her feel belittled and demeaned.³² In the Kanye programme, the caregivers indicated very little consultation, especially between them and their managers.⁷ To reduce the conflict between the caregivers and the client, there should be adequate consultation between the two parties, the care authorities and the caregivers, and between the caregivers and their clients.

Poverty and a lack of food are factors that have been found to beset care giving, especially much of the developing world.^{8,26} Studies in Kweneng found glaring poverty among the caregivers, as evidenced in the lack of even the most basic necessities, with a lack of food being the gravest.²⁷ Dr Salomao, SADC Executive Secretary, feared that the rollout of ARVs in Botswana may not achieve its desired results if food security is not addressed adequately. According to him, “There is no point in giving people ARVs on empty stomachs”.³³ The Government and other care managers need to address the challenge of food baskets

for ARV clients. The food baskets need to meet the clients' nutritional needs if the ARV and CHBC programmes are to succeed.

The Kanye caregivers' care giving was severely challenged by the inadequate care packages. Using the benchmark of the care package that caregivers used to receive some years back, as recommended by the Government,³⁴ the researcher found that almost 50% of the contents of the care packages were either missing or were not available at the clinics. The unavailability of the care packages and sanitation amenities poses a risk of contamination and infection to caregivers in Botswana. This presents a human rights abuse and dilemma, as those who take care of others face risk from their volunteering occupations.³⁵ Literature abounds on the fact that a number of diseases and infections, including HIV infections, have been documented to be transmitted by mere contact with the body fluids and secretions of patients, and hospital waste abounds in substances soiled with the body fluids and secretions of patients suffering from such diseases. Unskilful handling and disposal of clinical or hospital waste could also be catastrophic to the health and wellbeing of the community.³⁶ Other studies have found that the management and disposal of clinical waste in many care programmes have continued to be a thorn in the flesh of the caregivers.^{35,37,38} This is due either to a lack of policy, or the failure to operationalise it, inadequate community education on the subject, neglect, and a lack of adequate facilities, leading to unprofessional and ineffective ways of disposal and handling. This has borne grave hazards that compromise the quality of care in the programmes. This is especially due to a lack of proper government machinery to ensure the availability of care package facilities in the medical health institutions, and also to a lack of money to buy these necessary inputs.³⁵

The Kanye caregivers were not given adequate counselling to enable them to overcome their care-giving stresses and dilemmas. The impact of psychological wellbeing has a great bearing on the caregivers' productivity and on a reduction of the stress and confusion that abound in care giving.^{3,39} Inadequate counselling was demonstrated by some caregivers breaking down in tears while explaining the psychosocial environments they are exposed to. A lack of counselling and psychological nourishment, therefore, is one of the reasons contributing to low quality care in the programme. Counselling helps a caregiver to come to grips with the reality of the situation, makes him/her feel he/she is not "going crazy", instils hope and confidence, and makes him/her free to seek support and share with others, with the result that the psychological and emotional burden is reduced. The Government, care managers and other care-friendly organisations need to be armed with adequate and high-quality counsellors to help reduce the psychological dilemmas that engulf care giving. This could reduce the stress that abounds in care giving.^{8,39}

The Kanye caregivers complained of inadequate support from family members, relatives and their communities in general. Community support for care giving is necessary due to the weak institutional support for the sick in developing countries.²⁶ The lack of community assistance is unfortunate and undesirable, and presents a departure from past practice, when community networks afforded help to the sick.^{8,40} It is also an unfortunate scenario, particularly when many countries and their leaders, especially in Africa, are encouraging the spirit of volunteerism to foster the helping process. In Botswana, the spirit of volunteerism (*boithaopo*) and humanity (*botho*) is being appealed to in a nationwide call for the citizens to fulfil their spirit of caring and being compassionate, as espoused in the country's vision for 2016, the fiftieth anniversary of its independence.⁴¹

Studies done on care giving in Kweneng, Botswana found that caregivers felt unsupported by their families, relatives and the community at large,²⁷ while research findings from Zimbabwe suggest that care programmes are not supported by the communities. For example, the Chirumhanzu CHBC is not supported by community chiefs, who demand to be paid for their involvement.⁴² There is a need for continued advocacy by government leaders and civil society bodies for increased volunteerism. This is likely to encourage the young to assist the elderly, with the result of reducing the stresses associated with care giving.

Conclusion

The care-giving environment in the Kanye programme is stressful because the programme suffers organisational and coordination challenges; has inadequate care-giving provisions; and most caregivers cannot adequately afford the care-giving tools and food with ease. The caregivers are not motivated and are poorly equipped in terms of skills, both emotionally and psychologically, and all these factors interplay to have a negative influence on the quality of care. The programme calls for government intervention and for other organisations involved in care delivery to increase their assistance, monitoring and surveillance of service delivery in order to improve the programme's service delivery.

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