

## A Case Study Evaluation of the Training Gaps among Palliative Caregivers in Botswana Community Home Based Care Programs (CHBC)

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**ABSTRACT** The aim of the present research is to evaluate the training gaps and challenges within the Botswana community home based care programs exemplified by an empirical case study. The study used qualitative paradigm; was exploratory in nature and used case study design; and entailed interviewing 82 palliative primary caregivers in 10 focus groups and five CHBC nurses on one-to-one in-depth interviews. An interview guide served as a data collection instrument for both the focus groups and the interviews. Findings indicated an array of training gaps and challenges such as: lack of a caregiver training arrangement in the CHBC program; inadequate training of the caregivers; caregivers' inadequate skills in handling and disposal of clinical waste; complaints of primary caregivers being discriminated in training in favour of for community caregivers. The CHBC program needs: a comprehensive caregiver training to increase caregivers' understanding of the care giving field generally; training of caregivers on gender mainstreaming, self-care, management of clinical waste, and in income generating activities. Balancing training opportunities between the palliative primary caregivers and community palliative caregivers (volunteers) has been found critical.

### INTRODUCTION

The horrendous and pinching effects and dynamism of HIV/AIDS in Botswana, whether globally, regionally, nationally, and locally, have challenged all the sectors of the economy calling for increased effectiveness and efficiency in facing the epidemic (National AIDS Coordinating Agency (NACA) 2008). Meeting the palliative needs of people living with HIV and AIDS in health facilities or community home based care programs calls for preparedness of the health officers and palliative caregivers (Uys and Cameron 2003). For effective care of people living with HIV and AIDS in community home based care programs, it is absolutely important that caregivers adequately handle aspects of care such as oral care, hygiene, nutrition, and handling and disposal of clinical waste (Kang'ethe 2008).

Further, the need for palliative caregiver preparedness may be urgent given the fact of continued increase in the HIV/AIDS prevalence in Botswana and other Sub Saharan African countries. For instance, the increase of the population based prevalence from 17.1% in 2004 according to the 2005 Botswana AIDS Impact Survey (BAIS) report to 17.6% as indicated by the

2008 BAIS III survey results released in May 2009 sent a wave of confusion, dilemma and despondency, especially after a national and successful roll out of the anti-retroviral drugs (ARVs) (Central Statistics Office 2005, 2009). This meant possible increase in the number requiring assistance in community home based care programs. For instance in 2009, the country recorded 113,000 with advanced HIV and AIDS (Ministry of Health/JHPIEGO 2009). Ironically, the country has internationally been applauded for achieving the WHO "3x5" targets. According to WHO, Botswana was able to access its quota of 55,000 persons of people living with HIV/AIDS with ARVs by the year 2005. According to the WHO targets, developing countries were tasked with the responsibility of ensuring that at least 3 million people living with the virus were accessed with the ARVs (UNAIDS/WHO 2005).

Diverse literature about the palliative caregivers running these community home based care programmes in Botswana suggested that many are elderly, illiterate and economically challenged (MOH/JHPIEGO 2009), while challenges of hygiene, clinical waste management and handling, and low quality of care have been documented (Kang'ethe 2008). Requisite palliative caregiver training may range from sexually trans-

mitted diseases (STD) control, especially the syndromic management, counselling, testing and community care to behaviour change, management and planning. However, in many care settings, providing quality courses and other training opportunities is a tried and tested way of increasing the effectiveness and productivity of management, workers and volunteers (UNAIDS 2001). Exploration, assessment and evaluation of training gaps and challenges are, therefore topical, timely and pivotal. This could help policy makers and practitioners on the ground to put safety valves to the CHBC programs to better the palliative caregivers' performance. Inarguably, community home based care programmes in Botswana were institutionalised to complement the congested health services (Munodawafa 1998).

### Study Rationale

The rationale of the broad study from which this research is drawn was to assess the contributions of the palliative caregivers in CHBC programs in Botswana looking at Kanye CHBC program as a case study. However, this research seeks to discuss and explore the training challenges inherent with the volunteer palliative caregivers and therefore the impact the state impacts on the CHBC program. The findings are likely to bring in policy changes to bolster the state of palliative care giving and therefore skill improvement among the palliative caregivers. This would, hopefully lead to an improvement in the way people living with HIV/AIDS and other terminally illnesses are taken care of.

## METHODS AND SETTINGS

### Research Design

Qualitative research paradigm and a case study design were used in the study. Qualitative design facilitates collection of information from the participants' views, beliefs and their perceptions of the phenomenon under investigation (Rubin and Babbie 2008). Qualitative design targets to understand the process of the phenomenon under study as opposed to the outcome (Rubin and Babbie 2008). Qualitative research is concerned with meaning, that is, how people make sense of their lives. Participant observation was used, and is an important aspect

of the qualitative design to capture the mood and temperaments of the caregivers (Rubin and Babbie 2008).

### Research Instruments

An interview guide was used to steer 10 focus group discussions (FGDs) with palliative caregiver participants. The interview guide consisted of unstructured questions to guide the discussions. The instrument had been tested and refined during the pilot study conducted before the study kick off. Further, one-to-one in-depth interviews were conducted with the five nurses using the same interview guide that only differed slightly with the one for the caregivers. Nurses formed the caregivers' supervision team.

### Sample Selection Criteria and Procedure

All the 140 samples from the whole sampling frame of registered primary palliative caregivers in Kanye informed the sample selection, with eighty-two (59%) of them turning up for focus group discussions. The focus group discussions facilitated the collection of qualitative data on the views, attitudes and thinking of the caregivers pertaining to the contributions of palliative caregivers and challenges and gaps inherent in the program such as training. Five CHBC nurses were included into the study and were subjected to one-to-one in-depth interview. Ten focus group discussions in total were held, with the size of the groups ranging between 6 and 12. Each respondent was involved only once in the focus group discussions. The author conducted only one session in a day to get time to visit the caregivers for the next day session. The CHBC register in each clinic and the community caregivers (who supervised and helped the primary palliative caregivers in their care giving tasks) helped to identify the number of the primary palliative caregivers served by each clinic, and hence, made the sample grouping for the FGD easier.

### Ethical and Legal Requirements

To ensure that the study was politically correct, the researcher had complied with all the research permit application procedures from the Human Research and Development Committee Board (HRDC), and had, therefore, been issued

with the research permit. The researcher also consulted the Southern District Council (SDC) to allow data collection in the district. The researcher held several briefings and discussions with the selected samples explaining all the study processes, objectives and goals culminating in those who agreed to participate in research signing consent forms. The researcher had promised to treat all the respondents in a dignified manner, treat all the information anonymously and confidentially. Respondents had also been informed of their rights and freedom to withdraw voluntarily if they wished to do so if felt uncomfortable with research proceedings.

#### **Data Analysis, Interpretation and Bias Reduction**

Data analysis used thematic content analysis. Memo writing techniques, words, diagrams, charts, quotes, themes, analogies, proverbs, jotted notes and tables and figures were used as the main tools for data analysis (Rubin and Babbie 2008). The two sets of information from the caregivers and nurses were taped and then transcribed. The huge stacks of crude data were sorted, rearranged and reduced to manageable categories and themes using coding process (Rubin and Babbie 2008). This formed the basis of analysis.

As a bias reduction measure, the results from the pilot study involving five palliative caregivers and one nurse that preceded the study had served to remove ambiguities in the instruments. This contributed to reduction of the study bias and improvement of data reliability, validity, credibility and trustworthiness. Double translation of the instruments, that is translation from English to Setswana, and then from Setswana to English by two independent translators, the two parties coming together to settle on the difference had also contributed to refining the data collected and hence contributed to bias reduction. Besides, the two sets of collected data confirmed, contrasted and cross checked each other. This served to increase data precision and data bias reduction.

#### **Research Domain**

The data for this research was obtained from empirical research done in January 2006 at Kanye village. The 2008 population estimate for the area was 41,563 (CSO 2008). The village has a big

Seventh Day Adventist (SDA) referral hospital, five clinics and two health posts. The research domain was chosen as the area was experiencing a higher HIV prevalence rate of close to 30%, and was progressively experiencing a high death toll among the CHBC clients (NACA 2005).

### **FINDINGS**

#### **Profile of the Volunteer Palliative Caregivers**

##### *Age, Gender and Educational Dimension of the Caregivers*

Study findings confirmed that while the youngest caregiver was 18 years, the oldest was 85 years, with 46 (56%) being 50 years and above; and 25 (31%) of them falling in the 30-49 age bracket; while 11(13%) were in the 0-29 age bracket. The study revealed that most caregivers being women and, especially, those above 60 years indicated being financially challenged and physically not strong enough to stand the care giving demands. This led to their psychological disillusionment of care giving role. Eighty-eight (88%) of the caregivers confirmed they had no any income to support themselves making them suffer immense poverty. This made caregiving a daunting and an uphill task. They, therefore, recommended ways of increasing their care giving knowledge and skill as one of the ways that could improve their care giving conditions.

On literacy, 74% of the caregivers had either never been to school or had only primary level education; 21% had secondary level education, while 5 % of the caregivers had tertiary education. Caregivers indicated that their illiteracy impeded their care productivity and that the government and care managers needed to consider training them especially on the job training. This was to enable them to adequately track the disease of their clients and follow the medical and hygiene protocol.

On gender, findings indicated that the program faced serious gender skewed dimension with 80 caregivers (98%) being women and only 2(2%) caregivers being men. Majority caregivers who were women complained that care giving process was exploitative because it already added burden to their other domestic chores. It contributed to feminization of their poverty (Kelsey 1998; UNDP 2008).

### **Inadequate Training to Caregivers**

Most of the Kanye study participants indicated that the program had no training program, nor had the caregivers been trained to handle the challenges of care giving. Most of the caregivers, especially the elderly ones lamented that they were not well placed to handle some aspects of care, nor did they understand HIV/AIDS disease adequately. This explained the enormous caring challenges they faced. In the absence of any training, caregivers claimed using their God-given intuitive powers to perform care. They also claimed that the health personnel were not coming to assist or give them direction as far as caring was concerned. They, therefore, recommended for periodic on the job training. The following sentiments were expressed.

*"We have not had any care giving training. We use our natural God-given instincts to do care giving", "The health personnel do not come to supervise or direct us in care giving"*

This could possibly explain why care giving quality has been going down progressively as indicated by the continued high death toll in the program.

### **Primary Caregivers Should be Prioritised in Training before Community Caregivers**

Majority of the research respondents complained that they were denied training in preference for the community caregivers, who served as their supervisors and helpers in taking care of the sick. This they felt was discrimination and unfair prioritization because they needed care knowledge more than the community caregivers (so called volunteers in Botswana context). However, they confirmed having heard of training carried out in 1998 to some primary caregivers and volunteers (community caregivers) who were no longer in the practice, or whose patients had long died. Other than that training, they reported knowing that their colleagues, the volunteers were frequently invited for some training. Many were caught echoing the following:

*"We feel we need training more than the volunteers (community caregivers). We are the ones with the clients most of the times."*

### **Training Caregivers in Handling and Disposal of Clinical Waste Critical**

Close to half of all the research participants lamented that because of the inadequate knowl-

edge pertaining to the HIV/AIDS, they faced the risk of contracting it through contagion, and possibly meeting their death. This, they explained was exacerbated by lack of most tools of the care package in the clinics. The participants were especially emotionally engulfed when asked how they handle and dispose of clinical waste. They indicated that they were poorly equipped and no effort was made by the health authorities to come and teach or train them on the subject. The process of clinical waste collection, they said was complicated by acute transport problem. Even though the red plastic bags were available to the caregivers to put the clinical waste, they had to physically carry them on foot from their homes to the clinics where the council vehicle would collect them. They lamented that the carrying of the clinical waste to the clinic was both cumbersome and was stigmatized by community members. They explained that sometimes the clinical waste at the clinic was not collected in time, and coupled with the fact that the storage was small or unavailable altogether, posed environmental and clinical challenges. The issue attracted the following comments:

*"We are all going to die from contagion by catching the disease of our clients. We even do not know our status".*

*"The health authorities do not bother to come and teach or train us on the subject of handling and managing clinical waste."*

*"The care package tools to help the sick are no longer there. We are not helped at all".*

### **Training of Caregivers on Self Care Critical**

Majority of the study participants indicated the need to be educated and trained on self care. They advised that it would be vital for the program to have a schedule or a program for periodic training of the clients on various aspects of care giving from hygiene, self care and medical compliance. Caregivers indicated that due to inadequate tools and necessary requisite items such as food, sometimes the phenomenon drives them into conflict between them and their clients. They advised that having training that can incorporate the clients will help resolve or reduce such conflicts. This attracted the following sentiments.

*"Training on self care can reduce our burden to the clients."*

*“We need a training that will involve the caregivers and their clients. This can help reduce some conflicts that we face as caregivers.”*

### **Gender Training to Engender Care Giving Tasks**

Some caregivers thought that due to the unwillingness of men to help women in caregiving, training sessions specifically tailored for men could possibly help change their mind set and overcome the stereotypes and cultural norms that discourage their participation to caring tasks. They further indicated that male presence was necessary in caregiving as some care process such as changing positions and rolling a client over and over required assistance of men. The following quote was shared by many:

*“Having gender based training for men could possibly change their attitudes towards care and help us”*

A good number also indicated that men were also well endowed with economic resources compared to women and care business was likely to benefit from their cooperation and involvement.

### **Training on Income Generating Activities (IGA's) Could Buffer Care Giving**

Kanye study findings confirmed that 88% of the caregivers were poor and could not afford the clients good care. More than half of the research participants indicated that training on income generating activities could possibly bring them fortunes that will help the state of care giving, such as affording the clients' food with ease. They felt that it was important that their poverty was addressed if the care giving process was to be productive. They pointed out that if given support to start income generating activities, they would do it in tandem with care giving. This would raise their psychosocial satisfaction. The following sentiment was echoed.

*“Being financially helped to start income generating projects can bring benefits to care giving and possibly end our poverty”*

## **DISCUSSION**

The findings that most caregivers in Kanye CHBC program are elderly, illiterate, economically stressed women who need to be adequate-

ly prepared finds support from most CHBC programmes in resource constrained countries of the developing world (WHO 2002). In Namibia, for instance, studies by Niikondo et al. (2011) found that although the knowledge of the caregivers on HIV/AIDS was increasingly adequate, there was still lack of knowledge on isolated issues such as AIDS definitions and signs and how HIV works. They advised that training organisations in home-based care settings should emphasise the knowledge of AIDS definition and signs as well as of post-test counselling, consequence of poor adherence and facilities that issue anti-retroviral treatment. Research conducted in Thailand, Zimbabwe and Uganda on palliative care giving revealed that that over two thirds of elderly participants were the main caregivers of ill adults or orphans whose parents died of HIV/AIDS (UNAIDS 1999). With increased complexities presented by HIV/AIDS dynamism such as the need to fight off new strains; the need for oral hygiene; the administration of ARVs at home; as well as the need to offer an array of psychosocial support at home present daunting and uphill tasks to the elderly women making the informal caregiving safety nets untenable and unsustainable (McDonnell et al. 1994). Training palliative caregivers on care giving process could bolster their capacities to care for their clients as well as for their self-care. Knowledgeable palliative caregivers are also in a position to adequately understand the HIV/AIDS disease dynamics and help to reduce stigma. Arranging for routine and periodic on the job training could augur well in the productivity of the palliative caregivers (UNAIDS 2001).

On Kanye study findings of heavy female predominance, Kelesetse (1998) indicated that the phenomenon presents a burden to the female gender, as all the caring tasks are left to them. She indicated that the government has shifted its burden of caring for the sick and placed it on the shoulders of women. This is supported by other feminists such as Finch (1984) who see continued women preoccupation in caring as an exploitative process to the female gender. This has also been a strong reason contributing to feminization of poverty (UNDP 2008). Mainstreaming gender values through training and socialization of children when they are young at school could possibly ensure that boys and girls grow knowing and accepting that care giving is a preoccupation of

all, not for a particular gender. Changing, strengthening or enacting care giving policies to give room to paid incentives could possibly attract the young, and especially men in the care giving occupation. Advocacy education by leaders and civil society bodies is necessary to indicate that care giving should be a task for all in the society (Kang'ethe 2009).

Further, the findings that many caregivers were of lower education status finds support from a Ministry of Health/JHPIEGO study in 2009 (MOH/JHPIEGO 2009) and that of WHO (2000) that reported that most palliative caregivers in Botswana were usually elderly and of low education status. This author thought that ways and means of training the caregivers needs to be part of the CHBC program operationalization (Abbat and Meija 1988).

On inadequate training, as was the case with Kanye program, similar studies had more or less the same findings. In a baseline study for the community home based care programme for terminally ill HIV/AIDS patients in Botswana, only 10% of the caregivers had been trained by the family welfare educators (National AIDS Control Programme (NACP) 31 1996). In his study of Molepolole CHBC programmes, Munodawafa (1998) found there was no formalised training and that training was individualised and conducted by Family Welfare Educators (FWEs) during home visits as the need arose. This could have been faulted by the fact most FWEs were tasked to work in the clinics to help the nurses due to general clinic understaffing (Nurses Association of Botswana 2004). The government and care authorities need to take this issue to ensure that caregivers are trained periodically. Otherwise, the objectives spelt out by Government of making the CHBC programs to complement the congested health sector may not be achieved.

Kanye caregivers recommended self-care training. The road to a PLWHA achieving recovery and eventually positive living is the capacity to self-care themselves and relieving the palliative caregiver to get some respite (NAB 2004). This can be achieved if the caregivers are well equipped to trickle the skill to their clients. Self care, for instance, means that a client can be able to bathe by her/his own, can take medicine without failing, and be able to observe time and take food without coercion (NAB 2004). However, the effect of the antiretroviral drugs on very

feeble clients is working miracles as clients regain their energy to take care of themselves. This would be a goal that all the countries hard hit by the epidemic are striving to reach. Optimistically, achieving the self care training and being able to fruitfully apply it would possibly reduce the cost of care, especially the psychological and social costs usually borne by the caregivers (MOH/JHPIEGO 2009).

Training on physical care for both the client and the caregiver are equally important. This entails doing some physical exercises to ensure psychosocial health is maintained and can prompt and drive fast recovery. The researcher subjectively forms evidence that Placid Catholic Church in Mmopane village near Gaborone, in its holistic package to the PLWHA and their caregivers offers exercises to all the clients and their caregivers before the nutritious and a well balanced meal is served to them. This has seen many clients who could not formerly move recover and walk. The Catholic nuns and fathers who run the program are well equipped with exercise skills to impart to the caregivers and their clients. The role of faith based organizations in the battle against HIV/AIDS needs to be emphasized (Byamugisha et al. 2002).

Kanye palliative caregivers' findings indicated fear of contagion due to the fact that most of the care package instruments were not there, and the fact that they were poorly equipped to handle and dispose of clinical waste. Data on clinical waste management and handling in Botswana suggested that it poses a great challenge to care giving (Kang'ethe 2008). In their studies in Botswana, Muchiru and Florich (1999) found that disposal of clinical waste has been poorly handled with some caregivers burying the clinical waste underground while some try to burn it themselves. This poses a serious health hazard. Perhaps, the process of handling the clinical waste could be alleviated if the caregivers and all those involved in handling are well trained to handle them. Cases of dumped red plastic research bags full of clinical waste in the bush have not been uncommon in Botswana. Such waste could attract scavenging animals to open the content that would again attract buzzing flies. This, in Botswana, challenges the fulfilment of the environmental and vision 2016 campaigns that have been waged for a long time (Kang'ethe 2008; Vision 2016 1997). Mokgwaru (2001), in her study of the CHBC programs in

Botswana found that the program faces unprofessional and ineffective way of disposal and handling, and thus compromising the quality of care in the programme. However, this causes grave concern as a lot of researchers have proved that a number of diseases such as HIV/AIDS are scientifically known and proven to be transmitted by mere contact with body fluids and secretions of patients suffering from such diseases (Kang'ethe 2008). Improper disposal of clinical or hospital waste, therefore, could be catastrophic to the health and well being of the community. Training all the caregivers and other personnel working in close proximity and contact with clinical waste should be instituted and waste handling process taught to avoid direct possible infection through contagion (Abbat and Meija 1998).

Kanye palliative caregivers recommended having a gender training to persuade men to change their mindset and accept to co-participate in care giving with them. Lekoko (2009) advocated for diluting of cultures and patriarchy if societies would achieve gender equality and equity. This is critical to achieving Millennium Development Goal number three as enshrined in MDGs inventory (UNDP 2004). Training on gender or gender mainstreaming to engender the care giving norms, cultures, attitudes, and stereotypes would be pivotal as the increased rate of the pandemic calls for extra energy that men have. Such training should target all the institutions of learning such that care giving values are engendered and integrated into men's mindset right from childhood (Kang'ethe 2009).

As Kanye's study found that training the caregivers on income generating activities could bolster care giving, and food security, other studies had similar concerns. SADC secretary general, Dr Salomao has warned SADC countries to address the food security if the administration and implementation of ARV drugs are to succeed. He challenged that ARVs cannot work on empty stomachs (Agrinews Magazine 2006). Hope Worldwide NGO in South Africa, in an endeavour to solve the economic problems of its palliative caregivers helps organize income-generating projects. The organization seeks expert advice for the projects like vegetable growing around the clinics (UNAIDS 1999). Molweni AIDS Centre and Woza Moya caregivers in South Africa, for instance, have been trained in beadwork, fabric painting, sewing and vegeta-

ble gardening. The sale of their products results in substantial payouts to members, while some other members engage in selling second hand clothes provided by the centre. They do these activities hand in hand with care giving activities in the community (Byamugisha et al. 2002).

## CONCLUSION

Training palliative caregivers in all aspects of care giving is central to the success of care programs in Botswana. This will equip them to handle an array of challenges and problems confronting people living with HIV and AIDS. Training in income generating projects can be a poverty alleviation strategy among the caregivers; while gender training and mainstreaming could strengthen the involvement of males to co-participate in care giving in tandem with women. Training palliative caregivers is likely to improve the care giving environment generally and could reduce tension, especially, between the clients and the caregivers. This is likely to make care giving a less stressful undertaking and possibly a panacea.

## STUDY'S LIMITATIONS

Although, the research was done in 2006, the author who resides in Botswana and is in contact with care authority players in the area forms qualitative evidence that not much has happened on the ground. Further, a research commissioned by the government to investigate the challenges of CHBC programmes in Botswana in 2009 found most programs in dire need of training of the caregivers (MOH/JHPIEGO 2009). The researcher also considered training as a quality that should be on-going and infused into care programs.

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