

An Inventory of Empirically Grounded Strategies to Enhance Caregiving in Botswana

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ABSTRACT The aim of this paper is to explore empirically grounded caregiving strategies with the aim of computing a caregiving inventory to enhance caregiving capacities in Botswana. The study used a qualitative paradigm with a qualitative design in the form of a case study that was descriptive and explorative in nature. Convenience sampling methodologies were used to select one hundred and forty primary caregivers for study inclusion, but with only eighty-two availing themselves for a total of ten focus group discussions, while in-depth interviews were conducted with four nurses and their coordinator. An inventory of strategies to enhance caregiving was recommended and included improving and increasing the civil society assistance, psychosocial support and community ownership, fundraising and donor support, training, the referral networks, income-generating projects, care respite avenues, incentives, establishment of hospices and undertaking periodic research to establish gaps in caregiving.

INTRODUCTION

The application of the United Nations Community Capacity Enhancement Process (CCEP) tool in Botswana has the goal of improving and enhancing the productivity of service delivery mechanisms to widen the horizons of care quality. This is a social and community mobilization tool introduced by UNDP in the HIV and AIDS mobilization campaigns (Kang'ethe 2009a; UNDP 2004). It is a tool for mobilizing communities to realize optimal benefits from their social capital. It is in the quest for such goals and objectives that the government institutionalized community home-based care programs through contracting Makubalo and Msiska in 1995 to carry out a needs assessments of the CHBC programs, and further commissioning Munadawafa to evaluate Molepoplole and Tutume CHBC programs in 1998 (Kang'ethe 2009a; MOH/JHPIEGO 2009). This is enough evidence of the government's keenness to improve and enhance caregiving capacities. The government through former Minister for Health, Joy Phumaphi (1999-2002), had acknowledged and indicated challenges in caregiving prompting her to recommend government help in the future by setting up day-care centers to complement CHBC assistance and raise caregivers' psychosocial support and provide places for care respite. The Minister had also complained and indicated the operational challenges in the program, in that instead of family welfare educators being at the clients' place of abode to assist in caregiving, were stuck in

the clinics, largely due to inadequate staffing and coordination challenges (Kang'ethe 2006, 2009a).

The cardinal role of a CHBC program is to enhance prevention, care and support. This is in line with the country's national goals, Vision 2016 and robust ties with international Millennium Development Goal on prevention, care and support (UNDP 2004). Studies by MOH/JHPIEGO (2009) indicated that the program suffers many challenges such as, inadequate support from communities and health personnel, poverty of the caregivers making provision of care an uphill and an arduous task, an inadequate care package and other psychosocial services such as counseling. This, therefore, justifies a research paper such as this one to robustly identify and consolidate these challenges and gaps, and come out with an inventory of recommendations to enhance caregiving service delivery in Botswana's community home-based care programs.

Problem Statement

The researcher was motivated to consolidate an inventory of methods or strategies to enhance caregiving after empirically finding that most of his findings concurred with those of his erstwhile researchers such as Makubalo and Msiska in 1995, Munadawafa in 1998 (Kang'ethe 2009a). Khan and Stegling (2000) found more or less the same immense operational challenges such as inadequate psychosocial support, in-

adequate community and civil society, lack of caregivers' support groups, poverty and lack of income-generating projects, and inadequate care packages and support from the health personnel support. Such an inventory of strategies to overcome community home-based care (CHBC) challenges was likely to attract the government and other care-friendly organizations to act on the CHBC's prevailing challenges.

METHODS AND STUDY SETTINGS

Research Domain

The data for this paper was obtained in December 2005 and January 2006 at Kanye village. Kanye is an urbanized village according to administrative protocols. The 2008 population estimate for the area was 41,563 (CSO 2008). It is well endowed with adequate health facilities in that it has a big Seventh Day Adventist (SDA) referral hospital, five clinics and two health posts (NACA 2005).

Research Design

The study, descriptive and exploratory in nature, employed a case study qualitative research design. This is justifiable because the study sought to explore the thinking, feelings and lived experiences of a few samples of the primary caregivers on their contribution and to deeply understand caregiving challenges and gaps with the hope of coming up with strategies to redress them. According to Creswell (2009), qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem.

Research Instruments

Two slightly different interview guides were used, one to steer 10 Focus Group Discussions (FGDs) with the caregiver respondents, and the other one to administer the individual interviews with the five CHBC nurses.

Sample Selection Criteria and Procedure

Convenience sampling procedures were used to select all the 140 registered primary caregivers as they appeared in the CHBC register.

The researcher, in the direction of the nurses who formed caregivers' supervisory team had met all the primary caregivers in the clinics and the health posts (where their clients were served) in order to describe all the study's objectives and goals and to seek informed consent from them, spell out the interests of the researcher to carry out the research and the possible benefit to the care giving generally. The caregivers were ferried to Miracle Family Church premises (MFCC) to be interviewed. The researcher conducted the interviews with the nurses in their clinics and the CHBC coordinator from her office.

Eighty-two caregivers (59%) turned up for ten focus group discussions, while the five CHBC nurses who supervised the caregivers availed themselves for in-depth interviews. The CHBC register in each of the five clinics and the health posts, helped identify the number of the primary caregivers served by each clinic and hence made the sample grouping for the FGD easier. This eased the process of involving and making the caregivers participate in the study.

The caregivers' selection criterion and grouping, disregarding age and gender was based on the caregivers' clinic or health post proximity and where one was being served, with some clinics constituting more than one focus group discussions. However, the CHBC nurses were each interviewed from their place of work. Jotting down notes, probing, questioning and audio taping information from the respondents formed the strategies for collecting the data. Quotes, words, case stories, experience episodes and notes were used to inform data collection.

Ethical and Legal Requirements

The study observed all the requisite legal and ethical channels including holding briefings with the caregivers and the nurses for rapport and with those who accepted study inclusion signing consent made in Setswana, the researcher promising maintenance of confidentiality and anonymity of the data, and to treat the respondents with due dignity without any duress during the discussions. Respondents were informed of their right and freedom to withdraw voluntarily if they wished to do so or felt uncomfortable with the research proceedings. The researcher had complied with all the research permit application procedures from the Department of the

Human Research and Development Committee Board (HRDC), which is the ethical assurance board of the Ministry of Health concerned with research.

Data Analysis and Interpretation and Bias Reduction

The study used a content thematic analysis wherein both the information from the focus group discussions with the primary caregivers, and in-depth interviews with the nurses was taped and then transcribed with the purpose of looking for concurrent information to form themes. With the use of codes, the huge piles or crude data was sorted, rearranged and reduced to manageable categories. This formed the basis of analysis while tables and graphs were used to record the data and therefore the findings.

Data Credibility and Trustworthiness

The results from the pilot study involving five caregivers and one nurse that preceded the study had served to remove ambiguities in the instruments, and had helped focus the study more. This contributed to reduction of the study bias and improvement of data reliability and validity (Creswell 2009).

OBSERVATIONS AND DISCUSSION

Profile of the Caregivers

While the youngest primary caregiver was 18 years old, the oldest was 85 years. Age was found to be a crucial factor affecting caregiving with 46 caregivers (56%) being 50 years and above, and 28 caregivers (34%) being 60 years and above. The program was predominated by women, with 80 caregivers being women and only two men. One man was 70 years old and the other 35 years of age. Most study participants indicated that they were physically not strong enough to stand the caregiving demands, making coping difficult. The caregivers wished that their male counterparts could co-participate with them in caregiving. On literacy level, 29 (35%) caregivers had never been to school, 32 (39%) caregivers had only primary education, while 17 (21%) had secondary education. Only five percent of the caregivers had tertiary education. Most participants also indicated that illiteracy

was a challenge that negatively influenced caregiving quality as the lowly literate caregivers (who were also elderly) said they had problems with accessing caregiving information and education, following the medical and hygiene protocol, and following the disease progression of their clients. They wished that the program had on the job training programs on care, to raise the caregivers' productivity.

On an economic front, many lamented they suffered immense poverty. Seventy-two (88%) of the caregivers had no income to support themselves and they indicated that they found themselves occupied all the time in caregiving as they had nothing else to engage themselves into alongside caregiving. Caregivers complained that the communities have thrown the whole weight of caregiving onto them and that in the era of HIV and AIDS, it presents an overwhelming experience. The government in collaboration with NGOs in the care field need to come out with workable strategies for income-generating activities (IGAs), especially those that can be done in caregivers' or clients' compounds, depending on where care is given. Chicken rearing can make a good example of such IGAs.

Poverty and Lack of Income-Generating Projects Beset Caregiving

Almost all the Kanye caregivers indicated that poverty was seriously besetting their caregiving process. This, they said, emanated from the fact that only ten of them (12%) were involved in income generation projects. Many caregivers indicated that it was due to their poverty and therefore lack of income that they pegged their only hope from the food basket from the government and therefore building a dependence syndrome. They further indicated that if the government could help them start small income-generating projects, they would be self-reliant and therefore not wait for the food basket. The following was remarked by 3 participants,

Participant 1 and 2 (FGD 7,8,9) "Being helped to initiate income-generating projects will take away our poverty and reduce dependence syndrome."

Participant 4, 5 and 6 (FGD 1,3) "Our poverty has made us desperate and destitute, and yet we can do something worthy if helped to some extent."

Overwhelming Nature of Caregiving

Majority of the Kanye respondents unanimously admitted that caregiving was usually stressful and overwhelming because of the environment in which it was carried out. This, they said was because of inadequate community support from members of the civil society generally, inadequate psychosocial support such as counseling, their age and poverty, lack of motivation and incentives, inadequate physical environment and space of care, inadequate support from health personnel and social workers, and lack of adequate caregiving tools. They complained that caregiving was a process that would drive them to the graves fast as they suffered burnout with no chance for care respite. Their complaints and lamentations were recorded in the following quotes:

Participant 3 and 4 (FGD 8) "We do not see the health personnel coming to supervise or encourage us. We rarely get their help."

Participant 10 (FGD) "We do not get counselors to offer counseling in our caring duties."

Participant 6 (FGD 4) "Most of us do caregiving for 24 hours with no chance of care respite."

All the participants in all the ten FGDs, "Family members, relatives and friends help here and there, but inadequate help."

Skewed Gender and Age Gap in Caregiving

Kanye caregivers indicated that men and the younger people generally should help them in their caregiving tasks. They indicated that it was important that men, and generally the young people are encouraged to co-participate with them in caregiving. This is to ease their care load and therefore give them some care respite. This would make them replenish caregiving energy. This attracted the following sentiment:

Participant 10 (FGD 2) "Men and the youths need to be encouraged to help us in caregiving. This will give us a little respite."

Caregivers Lowly Regarded

Almost all the caregivers complained that they were not adequately recognized in their caregiving tasks as decisions to run the program were usually made by care authorities without adequately consulting them. They especial-

ly indicated being discriminated in favour of the community caregivers (usually called volunteers in Botswana) for most of the time.

Participant 4 and 5 (FGD 7) "The authorities discriminate us in favour of the community caregivers (volunteers), and yet we are the ones who carry out a lion's share of the caregiving work."

Lack of Incentives in Caregiving Lowers Caregiving Morale

Majority of the caregivers lamented the program's lack of incentives to boost their morale and motivation. They also made their suspicion known that lack of incentives kept men and the younger from caregiving. They made the following remarks:

Participant 4,6,7 (FGD6) "Incentives are not there to encourage us."

"If you want men and young women to participate in caregiving, give them incentives."

Inadequate Private Sector and Civil Society Assistance to Caregiving

Majority caregivers reported that only a few of the Kanye caregivers have benefited from or knew of the help assistance packages from the private sector, business community, or wealthy individuals. However, a few admitted that local businesses and supermarkets such as Friendly Grocers, Kanye Muslim Butchery, Score Supermarket, First National Bank, Standard Bank, Barclays Bank and Desai Supermarkets were giving donations to HIV and AIDS clients and their caregivers, although on a small scale. It was also revealed that these businesses preferred to help the orphans to HIV and AIDS clients and that could be the reason that most of the caregivers did not have the information. Most caregivers made the following sentiments:

Participant 1 (FGD4) "We do not know of the caregiving assistance from these civil society bodies. We are only hearing the issue today."

Participant 10 (FGD7) "These civil society bodies prefer to assist the orphans than the HIV/AIDS clients."

Caregivers Exposed to Inadequate Training

Majority of the Kanye research respondents indicated that they had not been trained in caregiving and hence used their indigenous intui-

tive knowledge systems (IKS) and grace from God to do the same. Respondents from different focus groups echoed the following sentiment:

All participants in all the 10 FGDs: "We do caregiving through God's wisdom and grace."

Many caregivers admitted that due to their low level of caregiving knowledge and lack of training, they were not adequately placed to track the progression of their clients' disease(s) and feared getting the disease through contagion. The following sentiments were expressed regarding inadequate care packages:

Participant 5 (FGD 8, 9,10) "We are all going to die from contagion. We do not even know our status."

Participant 8 (FGD 6, 7, 10)" We are not adequately placed to follow the disease progression of our clients."

However, a few elderly caregivers admitted having been given a few days' training in a workshop many years back. It was also reported that in some few cases, the CHBC nurses demonstrated how care business ought to be conducted, giving information on issues of house hygiene and nutrition, how to bath a patient, and how to keep one's client happy.

Poor State of Referral Networks

Majority of the Kanye caregivers reported being subjected to a poor state of the referral system, throwing them into a state of stress and confusion. They indicated that Kanye SDA referral hospital experienced inadequate human resource such that caregivers who took their clients to the hospital usually collected them back unattended, usually after waiting for the service the whole day. Inter-clinic referral and communication was also not good. This, the caregivers reported resulted in some clinics having some items in excess, while the neighboring clinics may have only inadequate supply of the same items. The caregiving process, therefore, presented a challenging experience causing pain and suffering to both the clients and their caregivers because of this poor state of referral system. The following sentiments pertaining to the referral system were captured in the FGD room:

Participant 7,10 (FGD 2) "Referral appointments in Kanye SDA referral hospital usually fail."

Participant 4 (FGD10) "The clinics suffer a poor referral system. While some clinics may

lack some items, the one may have excess of the items."

The five nurses also individually raised the same sentiments that the caregivers had raised. For example, the following sentiments were captured from the interviews.

All the participants in all FGDs: "Kanye SDA hospital is not delivering satisfactory service these days."

Participant 1,3,7 (FGD3): "There are several challenges with regard to the supplies of care package facilities."

AN INVENTORY OF EMPIRICALLY GROUNDED STRATEGIES TO ENHANCE CAREGIVING AND DISCUSSION

Need for Civil Society, Private Sector, Men and Youth to Assist in Caregiving

Findings indicate that it is pivotal and urgent that assistance to caregivers from civil society, private sector and private individuals, especially men and youths generally be increased. The call is in line with one of the Vision 2016's tenets calling on the Batswana to be a caring and compassionate (Kang'ethe 2009a). The call is also in line with Kofi Annan, former UN Secretary General who emphasized the need to involve everybody in the job of fighting HIV/AIDS at the UN General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001(UNDP 2001) by challenging all to recognize and prioritize AIDS as a problem for all. Importantly, the NGOs and CBOs can assist communities through community mobilization and advocacy to understand the need to assist caregivers in their caring job so that they do not get overwhelmed or suffer burn out (Kang'ethe 2010a).

Improving and Strengthening Community Ownership of the Program

Community ownership of the program needs to be strengthened by having all the community members interested and offering assistance without leaving the task to women alone. Engagement of men and the youths generally is especially pivotal (Kang'ethe 2010b). Cultural norms, values, attitudes and thinking that discourage men, and the youths in participating in the caring process need to be challenged by all in the society, government, civil society and individuals. This therefore means challenging and working towards dismantling gender stereotypes dic-

tating that caregiving is a preoccupation of the female gender (2010b).

Strategizing for Donor Support and Fundraising to Sustain Care Programs

The Kanye caregivers did not know about donor support. It is therefore recommendable that donor support and fundraising mobilization strategies are instituted and programed in order to sustain care programs. Withdrawal of donors from Botswana after it was upgraded to an upper middle-income class made most NGOs and CBOs that used to get funding from such donors be disadvantaged. Caregiving was not spared either by the detrimental effect (Kang'ethe 2010a). The donation assistance from the Melinda Gates and Merck and Company to Botswana to fight HIV and AIDS through ACHAP (African comprehensive HIV/AIDS Partnership), a public-private NGO, is highly welcome and other donors should be encouraged (ACHAP Update 2005). The advocacy and call for donor assistance and mobilization for sustainability of programs needs to be carried out and strengthened by the government, civil society bodies, private sector and private individuals. The resources can reach the caregivers through grassroots CHBC structures.

Initiating Poverty Alleviation Income-generating Projects

Kanye caregivers indicated that their caregiving was gravely beset by poverty. Perhaps this is largely because AIDS is a poverty friendly disease and thrives well in a poverty stricken environment. Assistance to caregivers by the government, civil society bodies and private sector to start income-generating projects fitting the age and strength of the caregivers is critical. Such projects could include pig keeping, poultry farming, bee farming, brick making and candle making. They can carry out the tasks in collaboration with other family members. The caregivers need to be rescued from poverty and therefore reduce their dependence syndrome (Kang'ethe 2009a).

Need for Care Respite and Relief from Burdensome Responsibilities

Kanye caregivers were suffering burn out due to increased burden and lack of care respite.

Importantly, the program under which a caregiver is working should help to assess his/her capacity professionally. This is because many caregivers may not be in a position to assess their breaking point especially due to emotional attachment and love they may have for their clients (McLeod 2007). Perhaps it is high time that the government set up day care centers for caregiver respite as hinted in 2001 by the former Minister for Health, Joy Phumaphi. This would make caregiving relatively an attractive preoccupation. Otherwise, it would be advisable, therefore, that most of the caregiving done by the caregivers be appropriately carried out in a caring institution or a hospice (Kang'ethe 2006)

Awarding Financial and Material Incentives

Kanye primary caregivers were not subjected to any incentives for morale and motivation purposes. It is now an incontrovertible fact that caregivers need incentives, either in the form of money or food items in order to raise their working morale. Provision of financial and material support is one of the pivotal measures necessary to bolster the caregivers' morale to improve quality in caregiving. Increasing morale of the caregivers must be considered as a priority in order to raise the quality and hence the productivity of the caregivers (Kang'ethe 2011a).

Improving Conditions of the Referral Network

Referral challenge was a grave bottleneck to caregiving efficiency and effectiveness. Most care programs, Kanye program not withstanding, face serious transport challenges. Transport is critically necessary to ease referral challenges. Providing cheap and affordable means of transport could alleviate these challenges. Availing bicycles and motorbikes to caregivers would be a milestone indicator of making the care process sustainable. These transport means could be of use to effect referrals, and also to get provisions from the clinics. However, such transport means need to be monitored closely to avoid misuse especially by men and younger family members (Kang'ethe 2008).

Strengthening Psychosocial Support

Psychosocial services were not adequately availed to Kanye caregivers. The psychosocial

support for caregivers needs to be availed through continued counseling, debriefings, health education and promotions, and supervision. Care managers, social workers and CHBC nurses should plan or create an environment in which caregivers can meet one another, share experiences, and achieve a sense of belonging. Visits and spiritual mainstreaming from pastors and church colleagues, sharing the word of God for encouragement are essential for spiritual support and psychological nourishment (Kang'ethe 2009b). This may make the environment of the caregivers much more manageable (Uys and Cameron 2003). Spiritual needs can also be met through regular meditation, relaxation and prayers led by peer caregivers.

Facilitating and encouraging an establishment of support groups by care managers and other organizations in the care field may be beneficial to caregivers. This is because support groups create a supportive environment where-in caregivers feel free to express their feelings, share challenges, experiences, and help prevent burnout and feeling overwhelmed, and are a forum to meet and access services like counseling from health professionals. Unrelieved grief and stress associated with caregiving can lead to diminished capacity in caring for others. Support groups reduce the isolation and emotional pain that can affect an individual's ability to provide care (Kang'ethe 2011b; Nurses Association of Botswana (NAB) 2004).

Instituting On the Job Training to Improve the Quality of Service

Kanye caregivers were not exposed to adequate training. It is therefore recommendable that the program institutes a strong training culture, especially on the job training. The training should be gradual as most caregivers have low literacy levels. Knowledge is power. It gives one confidence, control and an opportunity to make informed decisions. Training has a positive impact in planning, decision-making, managing stress and burn out among caregivers. Training encourages self-reflection, self-knowledge, self-actualization and strengthens the caregivers' coping mechanisms (NAB 2004; Kang'ethe 2015).

Establishment of Hospices to Reduce the Burden of Care in the Care Programs

Kanye respondents indicated that the care environment was taxing, burdensome, psycho-

logically draining and emotionally exhausting. Recommendation of alternative avenues of care such as hospices is therefore central and pivotal. Hospices are medical institutions with objectives to provide holistic care to terminally ill patients and their families, to provide a facility that relieves pain and other distressing symptoms to the patients, and to facilitate the development of a concerned community and environment sensitive to the needs of clients and their families, for both to attain a degree of mental and spiritual preparation for death (Manning 1984). Unlike a hospital, hospice care is not confined to a specific building, but takes place everywhere, even in a person's flat or house. It provides a number of services for terminally ill people, their caregivers and their families. Hospices will help take care and afford happiness to the bedridden patients before meeting their death (Byamugisha et al. 2002).

Holding Periodical Research and Evaluation of the Caregiving Programs

Kanye caregivers indicated the importance of care authorities to investigate the program operations in an endeavor to get to the truth and possible way out. It is therefore recommendable that operational research be carried out. Research is likely to identify problem areas and suggest alternative ways of solving inherent challenges. Research would reveal, for instance, the inherent needs of the caregivers, ways to motivate the community participation, and effectiveness or non-effectiveness of the caregivers. Research on the operationalization of the hospices and respite day care centers, how they can work hand in hand with the care programs all the time, strategies to have the services of hospices and respite day care centers be known to a larger community need be carried out. Further research to come out with a Botswana caregivers' operation model is ripe.

CONCLUSION

Incontrovertibly, drawing or coming up with an inventory to guide the operations of the community home-based care program in Botswana is central considering the challenges that the program faces. It will form a benchmark to assess the effectiveness and the efficiency of the program. It will therefore be a platform that will

act as a check and balance of the operationalization of the program's activities. It is therefore important that the components of the inventory are succinctly followed.

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