

Exploring the Stumbling Blocks Lying Along the Success of Community Home-Based Care Programs (CHBC) in a Few Countries of the Developing World

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ABSTRACT The paper aims to debate the stumbling blocks lying along the success of CHBC programs in a score of countries from the developing world in their quest to reduce or mitigate the impacts of HIV/AIDS and to impact the conditions of patients under the CHBC programs. The paper depends on a wide range of data sources and has picked the following challenges associated with CHBC programs: lack of funds to sustain the programs, inadequate government support, inadequate care knowledge, stigma and discrimination and donor fatigue. These academics suggest the following recommendations as an approach to reinforce and bolster the services for CHBC programs: training caregivers and availing sufficient funding for CHBC programs, enriched human and material resources for CHBC programs, reinforcing the importance of CHBC programs in communities, and building a strong partnership with other organizations and the community.

INTRODUCTION

Indubitably, community home-based programs especially in resource-constrained countries play an important role in the fight against HIV/AIDS. These programs have been premeditated to embrace all areas of HIV/AIDS prevention, care and treatment in the world (WHO 2002). According to the World Health Organization (1993), community home-based care is care provided to the terminally or chronically ill patients in their homes or their familiar communities. Such care services include palliative care, nursing care, counseling, psychosocial support, spiritual support, nutrition support and referral services. To this end, the South African Department of Health (2001) advises that the aim of home-based care is ultimately to promote, restore and maintain a person's maximum level of comfort, function and health, including care towards a dignified death (Payne 2009). Moreover, CHBC programs are broad and all embracing in relation to being deterrent, promotive, helpful, rehabilitative and analgesic. Campbell and Foulis (2001) reviewed existing research into home-based care in sub-Saharan Africa and found that multilevel factors undermine caregivers in performing their

roles, including lack of knowledge, skills and support, physical and psychological burnout, community stigma, and rejection.

In the researchers' arguments, successful implementation of CHBC programs in developing countries would be instrumental in improving the conditions of patients and reduce the impact of HIV/AIDS if only the stumbling blocks of the programs can be tackled. Regrettably, CHBC programs in some countries of the developing world face challenges, which hinder them from achieving their intended goals. The challenges include stigma and discrimination, inadequate care knowledge, donor fatigue, and lack of adequate support from the governments (Uys and Cameron 2003). These researchers, therefore, consider it pertinent to explore the services given to the patients and identify the pertinent challenges that CHBC programs face while trying to improve the clients' ill health. The paper, consequently, stimulates arguments and critiques the stumbling blocks lying along a successful CHBC program in some countries of the developing world like Zimbabwe, Zambia, South Africa and Botswana to mention a few.

Statement of the Problem

Whether viewed internationally, regionally or nationally, CHBC programs are increasingly becoming important as vehicles of palliative care to especially people living with HIV/AIDS and

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other terminally ill clients. In fact, a score of literature view it as a panacea considering the dwindling economic and human resource gaps that many countries of the developing world are apparently facing (Kang'ethe 2010a). However also, literature coupled with observations from the ground indicates that the programs in resource-constrained countries continue to face huge stumbling blocks making their operations less effective. These researchers, therefore, consider it important to explore the challenges and problems inherent in the programs in a few countries of the developing world. This, they hope would ring the bell to the policymakers to work towards addressing those challenges, either through policy enforcement, reformulation or restructuring.

Rationale of the Study

The main aim of this paper is to prompt discussions concerning the stumbling blocks lying along the successful implementation and operationalization of CHBC programs in a few countries of the developing world. The paper also aims to make suggestions of how such problems and challenges can be ameliorated.

Operational Definition

Panacea: While the word panacea means a remedy to all illnesses, it is hereby operationalized to mean a good and desirable state of affairs.

OBSERVATIONS AND DISCUSSION

Stumbling Blocks Impeding the Implementation of Successful CHBC Programs

Skills Gaps in Care

In most African countries, adequate knowledge and care skills have been identified as significant factors that can drive successful implementation of community home-based care programs (WHO 2002; Kang'ethe 2015a). To say the least, having adequate skill and possessing requisite knowledge about a profession or a domain makes the worker confident and therefore motivated to offer a service (UNAIDS 2001a; Kang'ethe 2015a). With the advent of HIV/AIDS, many countries of the developing world were

caught unprepared and therefore found themselves of workers in dire need of training a human resource cadre to handle HIV/AIDS (Kang'ethe 2015a,b). Since this implementation of training has been a dragged-out process due to the dearth of economic resources, many health settings, especially the community home-based ones have to work with unskilled elderly mothers. Although literature has documented that these mothers have been offering invaluable services, with some researchers such as Kang'ethe (2010a) contending that their services are a panacea amidst dwindling economic resources, lack of requisite skills and knowledge to handle HIV/AIDS has presented an arduous and an uphill task (Kang'ethe 2015). This is why Kang'ethe has recommended that these programs, in absence of money to train caregivers in full requisite courses, should consider on-the-job training package (Kang'ethe 2015a). Besides inadequate or unavailability of training, Kang'ethe (2010b) in his study in Botswana indicates that aging usually makes it difficult for some caregivers especially the very elderly ones to understand the dynamism of sickness, as they sometimes cannot adequately know if the clients are getting worse and effect the requisite referral (Kang'ethe 2010b) timeously.

To this end, according to Irish AID Health Development Network and Southern Africa AIDS Information Dissemination Services (2008), most CHBC programs and services have fallen short in terms of the quality and effectiveness of their service provision. There is lack of standards and quality assurance inherent in them. Inconsistent supply of CHBC kits and other supplies especially pose immense challenges to the programs. Just like the Botswana scenario above, low literacy levels coupled with advanced age of most informal caregivers makes it more difficult for most caregivers in many African resource-strapped countries to understand much information on care giving. For example, the Zimbabwean care lack generally resources fail to conduct refresher courses to equip these caregivers so that they can continue providing good care to patients (UNAIDS 2001a).

Stigma and Stigmatization Inherent in Care Programs

Stigma is the act of disapproving or victimizing an individual on the grounds of having characteristics that distinguish them from other mem-

bers. Stigma has negative impacts on the psychological and social wellbeing of the recipient, as it compromises one's dignity, self-worth and integrity (Kang'ethe 2015b; UNAIDS 2001b). It drains away somebody's confidence and integrity. The process of perpetrating or exercising stigma is called stigmatization (Kang'ethe 2015b; Uys and Cameron 2003). Stigma makes people unwilling to medication and assistance in time. Stigma is one of the challenges faced by people living with HIV/AIDS in many African societies, which results in many patients not disclosing their condition to their families and relatives (Kang'ethe 2015b; UNAIDS 2001b). Stigma often leads to marginalization, embarrassment, abuse, neglect and violation of rights of those stigmatized. In some cases, patients refuse to be referred to other facilities for fear of stigma. This further burdens their families psychologically as the act is likely to make the sick individual even worse (UNAIDS 2001b). Stigma in some contexts, such as Botswana, is believed to drive the patients and their caregivers to shun visiting the biomedical clinics and instead look for alternative treatment modalities whose efficacy may not be guaranteed (Kang'ethe 2012). In Botswana, for instance, in the early stages of the HIV/AIDS campaign when stigma was immense, it made people shun visiting their local clinics and go to other clinics far from their villages to avoid being discovered by the community members, while others opted to visit traditional healers (Kang'ethe 2009). Although one of the objectives of CHBC is to address stigma, stigmatization and discrimination, in Zimbabwe and South Africa unlike Botswana, the state appears to be a lagged out process (Kang'ethe 2015b). To the stigmatized, either those living with HIV/AIDS or their caregivers, the phenomenon leads to feelings of depression and isolation (Ministry of Health/JHPIEGO 2009). Similarly, moral judgment may stigmatize the PL-WHA. This is because many people still want to associate the disease with immoral activities. This, therefore make such people to see the PL-WHA as worthy of the blame of carrying the virus. It is important to note that the HIV/AIDS stigma can be experienced not only by people living with HIV/AIDS, but also by people who are suspected to be living with HIV/AIDS (POLICY Project 2003). Subjectively, information on the ground suggests that stigma is largely informed by facts such as backgrounds, values, beliefs and norms that different societies hold,

making it difficult for people to adjust to new changes with ease.

Painstakingly, HIV stigma and discrimination adversely affect every aspect of life for people living with HIV and their families. Therefore, stigma is a stumbling block to prevention, care and support as it discourages individuals from associating themselves to and helping people living with HIV/AIDS (UNDP 2004). Nevertheless, information dissemination on stigma against HIV/AIDS patients in various countries of the developing world is taking too long to take root in an endeavor to tackle or annihilate altogether. But because of the fact that countries experience stigma at different levels, it is important that those that are behind, such as South Africa, borrow a leaf from those that have moved some miles ahead in tackling the phenomenon (Kang'ethe 2015b).

These researchers contend that reaching many groups in societies such as the youth clubs, women clubs, men clubs, schools, health clubs, support groups and faith-based organizations may perhaps aid to accomplish to extenuate stigma. In the researchers' contention, great emphasis on reducing the state of stigma in countries where it is higher, such as South Africa, will depend on the strength of the information education machinery. This is because stigma emanates from misinformation, myths and stereotypes around the disease. If such information lapses are addressed, hopefully the process of extinguishing the fire of stigma can be expedited (Kang'ethe and Xabendlini 2014).

Inadequate Government Support

Regrettably, most African governments fail to give the HIV/AIDS campaign adequate support, or invest adequate resources. This, for most African countries, took place in the first decade of the disease due to denial or failure to understand the disease succinctly (Kang'ethe 2015b). This saw the disease proliferate unabatedly making many people succumb to HIV/AIDS. People also suffered the problem of ignorance and had to operate with myths and misinformation that perpetuated stigma (Kang'ethe and Xabendlini 2014). Umpteenth, a score of countries in the developing part of the world are still struggling to secure funds to raise the state of prevention care and support (UNDP 2004). Various reasons may be advanced. Funding was directed to other perennial problems such as poverty alleviation and putting up a health infrastructure to

surmount pertinent health challenges. In fact, this could explain the fact that most community home-based care programs that were instituted to complement government efforts in the fight against HIV/AIDS and other debilitating sicknesses are run with minimal support from the governments (Akintola 2004). In fact, despite their immense challenges from human resource to financial ones, some have managed to step up different aspects of the client's psychosocial needs, either through volunteerism, food donations or general community support. In resource-constrained countries, community home-based care programs are a huge panacea (Kang'ethe 2010a). This contention can be supported by empirical findings by Motana (2001), who reacting from the allegation that the program was a dumping process, found that it was indeed a panacea, enjoying immense community support.

However, since government support in some setting has been meager, the CHBC managers and NGOs should endeavor to draw up fund-raising proposals to seek funding, not only from foreign donors, but also from local sources. However, this calls for an environment of goodwill from the government. This is because sometimes governments in the developing part of the world have viewed NGOs and other semi-public bodies as sympathizers of opposition politics (Kang'ethe 2010c). This has made such bodies' operational environment a difficult one. However, on the other side of the coin, some NGOs have indeed used the opportunity to engage in corruption by diverting the funds they procure for public support into their own pockets.

Due to funding constraints, many CHBC programs are unable to implement and adequately deliver services to their clients due to insufficient resources, such as overhead funds, CHBC kits and educational material. This means that many governments in a score of countries of the developing world are failing to adequately support the CHBC programs. This could explain the mammoth death rate that was experienced in the first two decades after the advent of HIV/AIDS (Mohammad and Gikonyo 2005).

Donor Fatigue

Optimistically, international donors have played an important role in the fight against HIV/AIDS (WHO 2002). To say the least, their funding of the HIV/AIDS campaign has paid great dividends as the number of individuals infected by HIV/AIDS and those facing new infections

have decreased over the years leading to better improvements. Pessimistically, many donors who have been supporting CHBC programs in Africa have become weary in donating funds and also because of the economic meltdown that swept and affected many countries that were the sources of funding. This has had the impact of many care programs that rely on donors to go on their financial knees (Kang'ethe 2010c). In the researchers' contention, the economic crisis of the last decade that affected many western countries of Europe and America in particular also negatively affected the magnitude of funding to developing countries. Although they have still maintained their funding to projects such as male circumcision in Africa and other developing countries, other sources of funding have dwindled increasingly (Kang'ethe and Gutsa 2015). However, there is strong pressure from donors for short-term budget reductions, euphemistically referred to as "efficiency improvements". Some donors are steadily moving away from treating HIV/AIDS as an emergency, with dedicated flows of funds to more indirect interventions.

Observably, funding has also been negatively affected by the bad political climate in some countries. For example, in the orchestrated campaign to attack the western world, the government of Zimbabwe has not cooperated with the donors, but has instead tarnished their names and actions, convincing the Zimbabweans that donors want to extend their imperialism and colonize the African countries yet again. This has prompted an announced withdrawal of such donors. This donor cutting of funds has affected the CHBC programs that were receiving funds from these donors. However, donor inconsistency of their funds has also made planning very difficult. It is the researchers' thinking that developing countries need to seek homegrown solutions rather than waiting for funding from donors. Perhaps emphasis on indigenization of economies is critical, topical and timely. Countries need to harness and tap the indigenous resources using their indigenous knowledge systems (Kang'ethe 2011).

Way Forward

Training Caregivers and Availing Sufficient Funding for CHBC Programs

Although CHBC programs are playing a great role in the fight against HIV/AIDS, the re-

searchers contend that CHBC programs need to consider more education for caregivers. They should be accorded opportunities to attend on-the-job refresher courses to enhance their working capacity and morale. Training is believed to have an empowering effect making the recipients take control of their activities with ease and with minimal supervision. Training or capacity building creates capacities to build relationships among people and organizations with the result of enabling individuals take an active role in tackling new challenges in their communities and contribute to the overall wellbeing of their communities.

Availability of resources or undertaking resource mobilization is also a key factor that can empower community home-based care programs. To this end, donors in the caregiving field have collaborated with the governments in need to equip caregivers within income-generating projects to keep them out of poverty and also afford food for their clients. To this end some local programs have been able to mobilize local and donor resources for their sustainability. For example, in Zimbabwe, the Chirumhanzu CHBC program has six caregivers' support groups whose goal is to mobilize resources and increase the economic self-reliance of members by teaching them sewing (by hand and machine) and gardening skills. Some are also involved in raising chickens together.

Intensifying Anti-stigma Awareness Campaigns

Feasibly, all the governments of the developing world need to work hard with the health institutions and make sure that the information on stigma is disseminated to all categories of people in their countries. Importantly, countries should enact or formulate anti-stigma laws and by-laws to bring to book those who stigmatize people living with HIV/AIDS. Perhaps effective educational machinery needs to be launched to ensure that information on HIV/AIDS, its aetiology and its impacts are adequately understood. This is because stigma is a recipe of poor information dissemination, misconstrued information and information that fails to de-stereotype the stereotyped information. Correction of myths surrounding HIV/AIDS is of critical importance. Since the government may not be able to do everything, it is important to fund NGOs work-

ing with HIV/AIDS and other private bodies to effectuate information dissemination processes, and if possible training.

Governments Should Partner with NGOs to Support CHBC Programs

According to Jurgen (2012), the trends in HIV/AIDS-related research cannot be blamed on any country or government. However, the researchers suggest that the few countries in the developing world should make efforts to have a budget to finances CHBC programs. Furthermore, the governments should forge and foster partnerships with organizations such as the NGOs and private organizations that are working in the domain of CHBC. To this end the government of Botswana has benefited immensely through its tie-up with the African Comprehensive HIV/AIDS Partnership (ACHAP). ACHAP has for many years supported virtually all the HIV/AIDS campaign programs, hugely the provision of ARVS.

Fostering Indigenization and Local Funding to Replace Donor Funding

Evidence holds that donor fatigue is becoming a challenge for many African countries where CHBC programs have been implemented. This is due to the economic changes the donor countries may be experiencing. The researchers recommend that communities should be mobilized to provide local donations and funding to replace donor funding. This is because donor funding has proved to be unreliable and unsustainable. Perhaps working towards looking for homegrown resources, as an avenue of generating funding for CHBC programs can be a panacea. The NGOs in collaboration with the government should help CHBC programs initiate their own income-generating projects to enable them to financially sustain themselves. These researchers contend that people should not depend on donors or the government to assist all the time. Perhaps the communities need local leadership that will drive mobilization strategies to fundraise funds for the CHBC programs. A good example of a NGO supporting CHBC programs is the World Vision in South Africa that offers income-generating activities to the caregivers to help them cope financially. The income-generating projects take the form of grouping to

work together and enjoy the pool and encouragement effect. The NGO makes arrangements with agricultural experts to train and guide caregivers in food production for sustaining themselves and ensuring the sustainability of caregiving. In the same vein, Catholic AIDS Action in Kenya helps caregivers associated with it with some income-generating projects such as beadwork, sewing and making toys for sale.

The Theoretical Frame

Person-centered Approach

Carl Rogers propounded the Person-centered approach. This theory holds that people are essentially honorable, resourceful, have strengths and are able to understand and help themselves (Rogers 1951). Rogers contends that people in a relationship increase capacities to solve or resolve their problems. He emphasized that an effective helping process is characterized by people displaying empathy, being supportive, caring, being non-judgmental, and being trustworthy and lovely. These are the characteristics that good caregivers should have if they are to be passionate to their clients. Clients need do not need to be judged. They need to be encouraged and also be positively challenged to try to help themselves.

Rogers' belief in the client's ability of self-healing is complementary with many other theories that view the therapist's techniques as the most powerful agents that lead to change (Rogers 1986). Although there are many theories that can support this paper theoretically, Carl Rogers' person-centered approach emphasizes well that people who have problems including those that are sick with various illnesses like HIV/AIDS, have the potential to achieve personal growth and eventually self-actualize. If the clients receive guidance from professionals, these stumbling blocks faced by HIV/AIDS patients under CHBC programs can be successfully reduced. Therefore, HIV/AIDS patients in a few countries of the developing world should be educated and empowered by the caregivers displaying Carl Rogers' principles as described above (Rogers 1986).

CONCLUSION

Community home-based care programs are critical in supporting and improving HIV/AIDS patients to have a better life while mitigating the

impacts of HIV/AIDS in many developing countries. However, many stumbling blocks beset the processes of achieving strong and sustainable care programs. Lack of funds, inadequate care knowledge, donor fatigue and lack of government support are grey areas that need to be dealt with if CHBC programs in resource-strapped countries of the developing part of the world are to be sustained and bolstered. Perhaps homegrown solutions in various countries, such as affording local funding and communities' unleashing volunteerism to these programs could be in a huge way ensure a sustainable and a strong community home-based care environment.

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