

**Bringing HIV/AIDS Care Home:
Investigating the Value and Impact of Community
Home-Based Care in Botswana**

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I. Introduction

HIV/AIDS is a devastating reality in southern Africa, and the country of Botswana is one of its prime victims. Botswana has one of the highest rates of HIV/AIDS prevalence in the world with approximately 24.1% of the adult population infected (UNAIDS 2006). Life expectancy has fallen from sixty-five years in 1990-1995 to forty years in 2000-2005 (UNAIDS 2006). The mounting morbidity and mortality of the epidemic has placed increasing pressure on Botswana's public health sector. The needs of HIV/AIDS patients have created a demand for healthcare that is beyond the capacity of hospitals and clinics: in 2000, HIV/AIDS patients occupied more than one half of the beds in main referral hospitals (Stegling 2001, 243). In response to the growing epidemic, the Botswana government initiated community home-based care (CHBC) programs in 1996, a strategy that transfers some of the responsibilities of care from the health facilities to families and the communities in which patients live. CHBC programs have the potential to bring about important health and social benefits, but many worry that the development of CHBC has been an attempt to provide a quick and easy solution to relieving overburdened hospitals and clinics, without a real commitment to strengthening the services provided to those deeply affected by HIV/AIDS.

This paper will investigate the current challenges preventing the successful implementation of community home-based care programs for HIV/AIDS patients in Botswana. First, I will outline the main objectives of this study and present my research methodology. Next, I will survey and evaluate the current literature concerning the implementation of CHBC projects in caring for people living with HIV/AIDS in the region of southern Africa and highlight the different elements

that make up a successful CHBC program. I will discuss the rationale behind and framework for CHBC in Botswana and detail the specific challenges that CHBC programs are facing. My findings demonstrate that issues of poverty, financial constraints, fear of stigma and discrimination, overburdening of family members, lack of transportation, disjointed referral systems, inadequate support structures for caregivers, and lack of support for palliative care threaten the sustainability of CHBC programs in Botswana. I will conclude with a discussion of whether community home-based care is a viable and ethical solution to caring for HIV/AIDS patients in the context of Botswana, and offer some recommendations in regard to changes that could enable these programs to achieve greater success in their mission of relieving the suffering of patients and families coping with HIV/AIDS.

II. Methodology

Throughout the world, the emphasis of HIV/AIDS policies and programs from the start of the epidemic has been on prevention. Only in the past decade has awareness emerged at national and international levels about the importance of “care” and the development of an “international care agenda.” Many argue that the formation of care and support programs for HIV/AIDS patients has been a *reactive* rather than a *proactive* response (Ogden et al. 2004, 21). Efforts to create effective care programs have been criticized for being small in scale and haphazard, so I felt that it was relevant to study whether care for HIV/AIDS patients in the form of CHBC is being carried out successfully in Botswana. I outlined six research objectives that would be crucial in investigating this issue:

- To define community home-based care in the context of caring for people living with HIV/AIDS;
- To describe the essential elements of a successful community home-based care program;

- To discuss the reasons for the adoption of CHBC programs as a form of HIV/AIDS care in Botswana;
- To understand the framework and organization of CHBC programs in Botswana;
- To document the challenges and needs of HIV/AIDS patients, family members, caregivers and CHBC organizations in Botswana;
- To offer recommendations of policies and programs that will mitigate the current problems and enable programs in Botswana to achieve greater success.

To pursue these objectives I employed a qualitative methodology, surveying annual evaluative reports, case-studies, and local newspaper articles. This diverse array of sources provided important insight into issues related to community home-based care in Botswana. Evaluative reports assessed the functioning of specific CHBC programs in Botswana based on their annual budgets, types of services provided, client-to-care-giver ratios, and lack of essential resources. Case-studies included field reports by researchers who had conducted interviews with caregivers, family members, and other individuals involved in CHBC programs about their experiences. Local newspaper articles were also helpful in representing how CHBC is viewed in the local media and how much publicity this form of care receives. These articles discussed outside grants or funds being donated to specific CHBC programs and how these funds were being utilized to improve services and lack of resource problems. Overall, information and data was gathered from fifteen community home-based care programs serving the districts of Kweneng, Kgatleng, Mmopane, Old Naledi, Molepolole, Otse, Gabane, Bobonong, Kopong, Palapye, Kgalagadi North, Ngamiland, Gaborone Central, Gaborone West, and Broadhurst. This sample includes both urban and rural areas.

In addition to these sources, interviews with directors at three different CHBC programs, including Holy Cross Hospice located in Gaborone, Bobonong Home Based Care Association, and Kopong Home Based Care supplemented my research. With the consent of these informants,

all interviews were tape-recorded and then transcribed for later analysis. In utilizing documented research and interviews, I looked for parallels and common problems, in order to provide an overall assessment of the main challenges facing CHBC in Botswana. Background research on the impact of HIV/AIDS in Botswana and the country's current national AIDS policy was derived from recently published USAID, UNAIDS, and WHO reports.

In terms of limitations to this study, it is important to note that the challenges facing CHBC discussed in this paper do not affect each organization to the same degree; these were overall problems that appeared to be most significant and most repeated throughout the literature and in discussions with directors of CHBC programs. In addition, this study only used a small sample and therefore is not representative of all CHBC programs in Botswana. Another main challenge was difficulty in finding current government funding for CHBC programs and identifying CHBC organizations with efficient and accurate records of expenditures and costs. Current government budget speeches did not mention CHBC funding, so I was not able to find what portion of the national budget is being funneled into these programs. Furthermore, I was unable to develop a clear understanding of the role of anti-retroviral drugs (ARVs) and rates of adherence in CHBC programs. It was unclear to what degree each CHBC program has access to ARVs, and there appears to be a lack of coordination between the national CHBC and national ARV program. Due to this lack of information, the role of ARVs and issues of adherence in CHBC programs will not be discussed in great depth in this paper. Lastly, due to an inability to interview CHBC patients and the lack of academic material in this area, this study was unable to attain information about the extent of HIV/AIDS client satisfaction with their involvement in CHBC programs and whether the services provided by these programs are reflecting their felt needs.

III. Literature Review: Community Home-Based Care in Southern Africa

In order to understand the concept of community home-based care in the context of HIV/AIDS management in Botswana, it is important to survey and evaluate the current research concerning the implementation of similar CHBC projects within the wider scope of southern Africa. The current literature on CHBC covers a wide variety of areas and examines a multitude of issues. First, I will discuss the magnitude to which the HIV/AIDS epidemic is impacting southern Africa and how this has instigated a movement from hospital care to home-based care for patients. Second, I will define the meaning of community home-based care, discuss the different models of CHBC, and present the essential elements of CHBC programs focused on HIV/AIDS care. Next, I will highlight the concerns raised about whether or not CHBC is effective in caring, treating, and supporting people living with HIV/AIDS in developing countries. Lastly, I will explain how my research will contribute to the existing literature. This literature review draws upon case studies on the implementation of CHBC programs in southern African countries, CHBC conference reports, and manuals with clinical guidelines for the practice of CHBC published by the Red Cross, World Health Organization, and World Bank.

The global AIDS epidemic has caused vast suffering throughout southern Africa. This region has the highest HIV prevalence rates in the world, accounting for 32% of all HIV infections (USAID 2006). Four southern African countries—Botswana, Lesotho, Swaziland, and Zimbabwe—have national adult HIV prevalence rates exceeding 20% (USAID 2006). The mounting morbidity and mortality of the epidemic has placed increasing pressure on these countries' public health sectors. The care of HIV/AIDS patients has created demand for healthcare beyond the capacity of hospitals and clinics, forcing states to look for alternatives. In response, several southern African

countries have initiated CHBC programs, a strategy viewed as more affordable and attainable than hospital care. CHBC programs have the potential to bring about important health and social benefits for the patients, families, and communities involved, but many studies have questioned their effectiveness.

Most of the literature presents similar definitions of community home-based care, drawing upon the definition of CHBC provided by the World Health Organization:

Any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of CHBC is to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life. (WHO 2002, 5)

It is important to note that the practice of home-based care was an existing health services approach before the onset of the HIV/AIDS epidemic (Chaava 2005, 20). In Africa and throughout the world, provision of care and support to people living with HIV/AIDS was largely ignored in the first stages of the epidemic, as most effort was placed on prevention strategies. In response to the growing recognition of the need to develop an international care agenda, the World Health Organization developed the “Care Continuum” model in the mid 1990’s to promote a holistic approach to caring and supporting HIV/AIDS patients (Ogden et al. 2004, 21). Community home-based care was described as an important element under this system.

A number of different CHBC systems have been reported on in the literature by Uys and Cameron (2003) and Defilippi (2005). These authors discuss the three different models of home-based care for people living with HIV/AIDS in southern Africa. The *integrated model* links all service providers with patients and families through a continuum of care. Its goal is to build a strong support network among the patient, family, caregivers, hospitals, clinics, and non-governmental organizations. The *single service model* includes one service provider, such as a hospital, clinic, or NGO, that administers CHBC through recruiting and training volunteers and

linking them to patients and families. The *informal model* involves care for HIV/AIDS patients by family members with the informal assistance of their own social network. Family caregivers generally do not have any specific training, external support, or structured intervention. Both Uys and Cameron (2003) and Defilippi (2005) emphasize that for CHBC to be effective, the integrated model must be used—in their view, the single service model and informal model are ineffective in providing holistic care and support to the patient and family.

In the integrated approach, WHO stresses the importance of CHBC being implemented with a team approach to ensure that all the essential elements of care are included. This team should include the patient, family, health and social welfare personnel, community health workers, and volunteers (WHO 2002, 10). Governments and community organizations must then work to develop and run programs using each member of the team effectively. Mohammad and Gikonyo (2005) also argue that effective CHBC programs for people living with HIV/AIDS can only be achieved through a “continual cohesive commitment between communities, governments, organizations, and development agencies/donors” (7).

The growing trend of developing community home-based care services has meant a shift away from hospital-based care in southern African countries. This model is viewed by Stein (2002) and Chaava (2005) as more accessible and affordable than costly hospital inpatient care. Although CHBC is viewed as effective by the Red Cross (2005) and WHO (2002), much of the literature raises concern about whether the development of CHBC functions as a quick and easy “solution” to the overburdened health sector without a real commitment to strengthening the services provided to people living with HIV/AIDS (Jacques 2004; Stegling 2001). In the First Southern African Regional Community Home-based Care Conference held in Botswana, this question was raised: “Is home and community based care merely a mechanism to decongest hospitals and ease

overburdened and weak health infrastructures? Or is it a way to provide a holistic care that gives power to the patient, empowers the community and allows people to be cared for with dignity?” (HDN 2001, 14)

Ogden et al. (2004) contend that many CHBC services in southern Africa have been developed through unsystematic, needs-based efforts and argue that more emphasis must be placed on taking a more formalized, organized, and programmatic approach in establishing these programs. Both Jacques (2004) and Stegling (2001) explain that if administered effectively, CHBC programs have significant benefits, but there are limitations and potential challenges that need to be squarely addressed in order to make CHBC programs a success. The Red Cross (2005) argues that stigmatization and discrimination, prevention, and access to support, care, and treatment are inseparable and all these factors must be addressed in order to implement a successful CHBC program (6).

The existing literature explains that there are several elements that make up a successful CHBC program. According to WHO (2002), the first step in providing effective CHBC is to assess the patient’s environment and make sure that the basic needs of the patient and family are being met—this includes ensuring that families have adequate shelter, food, safe water, proper sanitation, and clothing (25). The majority of the literature emphasizes that CHBC needs careful planning and that it is crucial that operational partnerships and referral mechanisms are established at local, regional, and national levels upon implementation of the program (Defilippi 2005; Mohammad and Gikonyo 2005; WHO 2002). A variety of services must be available to patients and their families, including medical and nursing care, access to ARV treatment, health education, socioeconomic support, nutritional support, psychosocial support, and housekeeping (HDN 2001,

23). Care providers must also be given personal support, as the task of caring for an HIV/AIDS patient can be strenuous and emotional (Red Cross 2005, 8).

When the holistic approach is taken and all of these elements are established, CHBC programs yield significant health and social benefits (Jacques 2004; Stegling 2001; Stein 2002; Uys and Cameron 2003). As presented by Uys and Cameron (2003), some of these benefits include the following: care is more affordable for the family, as transport to hospitals and clinics and inpatient fees are reduced; care is less expensive for the government, as the number of patients in hospitals is reduced; care is more personalized and the patient is less likely to feel isolated from family and community; and patients are able to die at home, in familiar and comfortable surroundings. Both Stegling (2001) and Jacques (2004) highlight the important ability of CHBC to unite aspects of care with prevention, which are usually seen as two exclusive concepts. By including the family and community in patient care, it becomes possible to discuss prevention within the community. Issues surrounding HIV/AIDS are brought into the open, creating opportunities to clarify myths about the disease, lessen stigma and discrimination, and influence people to take action to ascertain their HIV status and change risky behavior (Stein 2002, 415).

Despite these benefits, the CHBC programs in southern Africa, as currently implemented, have faced several challenges. Jacques (2004) notes that poverty can act as a barrier to the provision of quality and that many patients are referred home without adequate assessment of their domestic environments. According to Mohammad and Gikonyo (2005), this poverty contributes to poor nutrition and shelter, causing caregivers to have to struggle to accommodate patients in a home lacking basic necessities. This burden of care usually falls on women, including the elderly and young girls in the family. In a study completed by Akintola (2004), it was found that women carrying the burden of caring for family members living with HIV/AIDS in South Africa were

suffering from exhaustion, malnourishment, and psychological distress. Akintola also pointed out that a 2004 UNAIDS study reported that two-thirds of primary caregivers in households surveyed in southern Africa were female; one-fourth of these women were over the age of sixty (2).

Additionally, Stegling (2001) argues that stigma and discrimination also hinder the success of CHBC programs. Although one of the objectives of CHBC is to address stigma, discrimination in many communities was not reduced, leading to feelings of depression and isolation among patients and caregivers (Stegling 2001, 242). Other sources point out additional problems, including a lack of properly trained personnel, lack of technical expertise, and lack of important resources (Mohammad and Gikonyo 2005; Red Cross 2005; WHO 2002).

The challenges and potential obstacles to success noted by these authors lead to a fundamental question: Does community home-based care for patients living with HIV/AIDS and their families—as currently practiced—ultimately relieve or worsen human suffering? Jacques frames the concern as follows:

Home-based care, while politically correct, expedient, and culturally relevant, embodies the germ of exacerbated human suffering for patients and care-givers alike, unless rigorously controlled and generously supported through appropriate allocation of material and psycho-social resources. (Jacques 2004, 191)

My research will focus on the current status of these programs in Botswana, with particular attention to the challenges and potential obstacles they face, and with the intent also to address this underlying question about suffering. I hope to make a modest contribution to the existing body of knowledge on the practice of CHBC for HIV/AIDS patients in developing countries. I will utilize my findings to offer recommendations on how the implementation of CHBC programs in Botswana can be strengthened.

IV. Community Home-Based Care in Botswana

Botswana's National AIDS Policy

The emergence and rapid spread of HIV/AIDS in Botswana over the past decade has had a devastating impact on the country's population. It is estimated that over 270,000 adults and children out of a population of only 1.6 million are currently living with the disease (UNAIDS 2006). The epidemic has already claimed the lives of over 18,000 citizens since its start, and approximately 120,000 children have lost at least one parent to the disease (UNAIDS 2006). In a UN assembly in June 2001, former president of Botswana Festus Mogae stated: "We are threatened with extinction. People are dying in chillingly high numbers. It is a crisis of the first magnitude" (PBS 2006).

After declaring the HIV/AIDS crisis a national emergency, the Botswana government initiated several policies and programs to fight the disease. In 1999, the National AIDS Coordinating Agency (NACA) was created with the purpose of mobilizing and coordinating a multisectoral response (NACA 2003, 18). In 2003, the government developed the National Strategic Framework to guide its response to HIV/AIDS through 2009. The framework put forth five goals: 1) prevention of HIV infection; 2) provision of treatment, care and support; 3) strengthened management of the national response to HIV and AIDS; 4) psycho-social and economic impact mitigation; and 5) a strengthened legal and ethical environment (NACA 2003, 23). It was stated that these goals would be achieved within the scope of Vision 2016, which aims to prevent any new HIV infections by the year 2016. CHBC falls under the second goal of provision of treatment, care, and support. The framework of these programs will be explored in the next section.

Adoption of CHBC in Botswana

The concept of community home-based care was first introduced in Botswana in 1992, when it became clear that the public health sector was unable to cope with the increasing number of patients suffering from HIV-related illnesses. During this time, the percentages of bed occupancy of patients with HIV/AIDS in the two main referral hospitals in Botswana, Nyangabgwe and Princess Marina, were 70% and 50% respectively (AIDS/STD Unit 1998, 2). In primary and district hospitals the rate was around 30% (AIDS/STD Unit 1998, 2). In several cases, patients were discharged from hospitals despite the fact that they still needed care (Folgstad 2002, 44). The development of the CHBC system officially began in 1996, with pilot projects in Tutume and Molepolole (Odek and Oloo 2007, 7). In explaining the importance of these projects, Khwezi Mbonini, a woman who was involved in their development, stated: “The projects could not have come at a better time. Sixty percent of beds were occupied by AIDS related illnesses and floor beds were being used, but hospitals still did not have sufficient capacity to provide proper care for patients” (Skillshares International 2002). These projects only lasted one year, due to lack of support and resources (Odek and Oloo 2007, 7).

In response to these failed projects, CHBC was placed under the guidance of the government’s National HIV/AIDS Strategic Plan. Under this plan, CHBC is the responsibility of both the Ministry of Health and the Ministry of Local Government, Lands, and Housing. The former is responsible for ensuring the “implementation, coordination, monitoring, and standardization of CHBC programs” (AIDS/STD Unit 1998, 6); the latter for ensuring that “sufficient financial, manpower and transport resources are available for the implementation of CHBC programs” (AIDS/STD Unit 1998, 8).

Under this policy, CHBC is coordinated at the national, district, and local level. At the national level, a CHBC coordinator based at the AIDS/STD Unit works with district level CHBC coordinators, who are assisted by doctors, nurses, community health workers, and volunteers. These CHBC staff work in partnerships with local nongovernmental and community-based organizations (Shaibu 2006, 90).

The number of HIV/AIDS patients registered on community home-based care has been increasing steadily since 1996. At the end of June 2000, the cumulative figure for clients registered on CHBC stood at 7,000 (Jacques and Stegling 2004, 178). In 2005, there were approximately 12,577 patients registered to receive CHBC services across twenty four districts in Botswana (NACA 2005, 22). Data on the current number of CHBC patients could not be obtained, but the following graph, published in a NACA 2005 March Report, is helpful in illustrating the scale of CHBC care throughout Botswana.

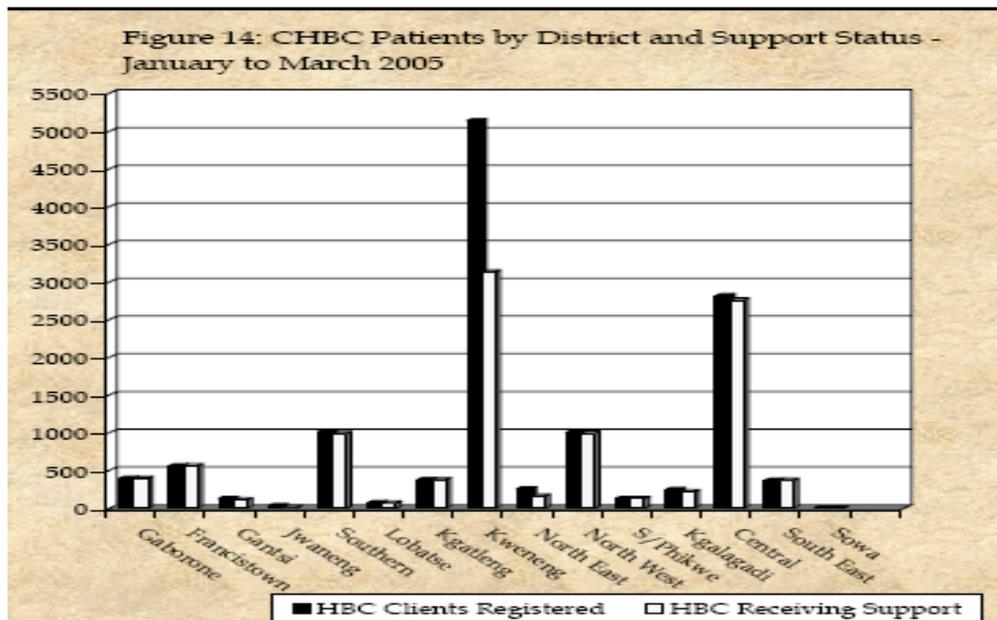


Fig. 1. Source: MLG-ACU May, 2005 NAC Report

Goals of CHBC in Botswana

The initial focus of CHBC programs in Botswana was primarily to relieve the congestion of public health services from increasing numbers of HIV/AIDS patients. Over time, there has also been an increased focus on developing national CHBC goals and guidelines. The stated objectives of the CHBC Program in Botswana are:

- i) To increase access of AIDS-affected families to skilled medical care, counseling and support on a regular basis;
- ii) To equip families with more skills in caring for their family members who are affected by HIV/AIDS; and
- iii) To increase the access of families with AIDS patients to home care supplies. (Odek and Oloo 2007, 7)

The framework of CHBC in Botswana emphasizes a holistic approach to care that involves the participation and support of many different parts of society. The former Minister of Health to Botswana, Joy Phumpahi emphasized that the success of home based-care depends on the community at large lending a helping hand and sharing responsibility in the care of those suffering from HIV/AIDS:

Home-based care is taking us back to the root of human co-existence. It reminds us that we all have the responsibility to one another. If we hold hands through this tragedy...we will be able to retain our humanity and will come out of this epidemic as a stronger community. (WHO 2002, 8)

A major rationale for the implementation of CHBC was the recognition that it is a more cost-effective form of care compared to inpatient hospital care, and that patients prefer to die at home. Additionally, the family is the traditional caring unit in Tswana culture, so it was believed that a program built on this structure was likely to succeed (Odek and Oloo 2007, 7). In initiating CHBC programs, the government stressed that the transition from hospital care to home care was an important way for families and communities to experience the reality of the disease. According

to the AIDS/STD Unit (1998), “Caring for patients with AIDS [in the home] is probably the best way for families and communities to perceive AIDS as a reality in the community and for their own lives” (6).

It is important to emphasize that CHBC is conceptualized and implemented in different ways throughout all of Botswana—all programs and communities have access to different resources and therefore do not all have the capacity to provide the same services. CHBC is facilitated through team visits to HIV/AIDS patients in their homes; services are provided free of charge (AIDS/STD Unit 1998, 6). The CHBC team is generally made up of nurses, doctors, social workers, volunteers trained in basic nursing care, and household family members. The range of services offered in each program differ, but generally include counseling and psychosocial support; provision of social services (financial, legal, and material support); and medical/nursing care (Ogden et al. 2004, 28). When reviewing the challenges currently facing CHBC programs in Botswana, it will be important to assess the extent to which this definition of providing holistic care is actually being implemented.

V. Main Challenges Facing CHBC Programs

Through this study, I found that issues of poverty, financial constraints, fear of stigma and discrimination, overburdening of family members, lack of transportation, disjointed referral systems, inadequate support structures for caregivers, and lack of support for palliative care are threatening the sustainability of CHBC programs in Botswana. These findings are presented thematically and followed by a discussion of the implications of these issues and what steps can be taken to improve CHBC programs in Botswana.

Poverty

Poverty is the main barrier in providing quality care to HIV/AIDS patients in the home (Shaibu 2006, 92). HIV/AIDS has severely detrimental effects on the economic sustainability of a household as the main income providers fall ill to the disease. Although Botswana is among the few African countries characterized as “middle-income,” the gap between the rich and the poor continues to widen. It is estimated that 47% of the population lives below the poverty datum line, 38% in urban areas and 62% in rural areas (Folgstad 2002, 39). When patients are referred home to receive CHBC services without adequate assessment of their domestic environment, caregivers often find themselves struggling to accommodate patients in a home lacking adequate shelter, food, safe water, proper sanitation, and clothing (Ngwenya and Kgathi 2006; Phorano et al. 2005; Shaibu 2006; Stegling 2000).

In two separate studies in the district of Kweneng, Stegling (2000) also found poverty to be the main obstacle to the provision of quality care. Out of thirty patients interviewed in one study, none held a paid job, and 85% of the CHBC volunteers were not formally employed. Many volunteers were earning a small income on the side through small-scale farming or running a tuck shop (245). Two of the patients lived in dilapidated houses and another lived in a plastic shack—environments clearly not conducive to appropriate care (246).

According to a study conducted by Phorano et al. (2005) in the districts of Ngamiland and Kweneng, households lacked basic facilities such as toilets, waste receptacles, and regular collection of solid waste. This resulted in the improper handling of soiled laundry and inadequate ventilation, thus increasing risk of infection among caregivers (161). Additionally, in a study investigating access to potable water in households receiving home-based care in five rural

communities in Ngamiland, Ngwenya and Kgathi (2006) found that these households were constantly faced with an unreliable water supply. The study revealed that households receiving HIV/AIDS care require more water—on average, households consume less than thirty liters per day, but caregivers with bed-ridden patients suffering from diarrhea needed an additional twenty liters to wash soiled blankets, clothes, and sheets, and sterilize bathrooms or toilets (672). During periods of water stress, it was observed that the bathing of the patients was reduced and sometimes he/she was given a “dry bath,” where only essential body parts and wounds were cleaned (674).

Financial Constraints

Community home-based care in Botswana does not receive wide publicity, and in terms of HIV/AIDS funding is not seen as attractive as vaccine initiatives and prevention/education programs (Folgstad 2002, 45). It is argued that CHBC is largely being sustained by the work of non-governmental and community based organizations, with minimal support from the government (Akintola 2004, 10). It was difficult to obtain information on the current amount of government funding for CHBC programs. However, one source mentioned that a budget of one million Pula (USD 250,000) was approved in 1999 to provide financial support on a case-by-case basis to NGOs and CBOs providing CHBC services (Folgstad 2002, 57). With scanty and sometimes delayed government funding, many CHBC organizations are forced to raise money on their own. For example, Kebonyemang Mosolomane, committee treasurer for Phuduhudu CHBC in Kgalagadi North states: “We raise funds through several activities to augment the little we get from the council. We usually organize concerts to raise funds and we do not wait for the money from the council...we were able to build two houses for some destitute persons through the money raised from concerts and sengaparile sales” (BOPA 2005). Although fundraising projects are essential, they can result in less time spent caring for patients. In a CHBC program in Mmopane

village, it was observed that volunteers were spending more time on beadwork to raise funds, lessening their time spent caring for patients (Shaibu 2006; 92).

Many programs are largely sustained by the work of volunteers because funds are lacking to hire paid workers. As the director of Bobonong Home Based Care Association said: “Without volunteers from the community, our program would cease to exist” (Interview A 2008). In an interview, the director of Holy Cross Hospice emphasized the need for additional resources:

The demand exceeds the supply. There are too many people in need of our service, but we cannot provide services to everyone. Limited resources infringe on the quality of services that we provide and our ability to maintain good quality care. We must rely on volunteers. For example, we cannot afford to hire a professional doctor. We rely on doctors who volunteer their time to evaluate clients. (Interview B 2008)

Several CHBC organizations stress that with increased funding, the quality of their programs could improve greatly. For example, Otse Community Home-Based Care emphasized that more money would help to extend services to reach the estimated five hundred people in need of their assistance (Setso Project 2008).

Stigma and Discrimination

HIV/AIDS related stigma and discrimination persists in Botswana; many people diagnosed with AIDS fear isolation and alienation from their communities. CHBC has become associated with “having AIDS,” causing many families to be reluctant to receive or ask for care from these programs (Shaibu 2006, 93). CHBC services are sometimes not utilized because of this stigma. Many needy households refuse government food baskets because “once you receive the food basket, everybody in the community knows that you are an AIDS patient” (Jacques and Stegling 2005, 181). Although more tolerant attitudes towards HIV/AIDS have been promoted through CHBC, discriminatory attitudes among family members still exist to a small degree. In Letamo’s

study (2003) on the prevalence of discriminatory attitudes toward HIV/AIDS in Botswana, one survey showed that when respondents were asked about whether they would take care of a family member with AIDS, 11% out of a sample of 4,147 respondents said they were unwilling (347). This was often due to myths such as believing the disease could be transmitted through sharing a meal (351). Although rare in occurrence, lack of support from the family can be severely detrimental to the goals of CHBC programs organized around an approach in which the family serves as the traditional caring unit.

Overburdening of Family Members and the Feminization of Care

Several studies highlight the common problem of family members becoming primary caregivers despite the availability of assistance from a formal CHBC caregiver, such as a nurse, doctor, or trained volunteer. According to Horman et al. (2005) “formal caregivers serve more as a complement to the household caregivers than as a substitute” (6). Even when formal caregivers provide CHBC services, family members generally spend more time per week assisting the patient. Usually, this burden of care is placed on the women and young girls in the family (8). In a study carried out in the districts of Kweneng, Kgatleng, and Old Naledi, Lindsey et al. (2003) found that out of thirty-five caregivers, thirty were female and only three male (493). Older women expressed feeling overwhelmed with the magnitude and multiplicity of tasks they had to perform—many suffered from exhaustion, malnourishment, depression, and psychological distress (486). Many also felt loneliness and isolation, as caregiving kept them within the house for most of the day (496). One mother testified “I cannot go to funerals or weddings, not even to church, because I have to be with him all the time, or most of the time...I can’t even go to the fields to plough” (497). In several cases, young girls were providing care to sick parents, resulting in many dropping out of

school or participating in illegal activities, such as prostitution, to provide additional economic support to the family (497).

In some cases, families only want formal caregivers to assist minimally, leaving intimate care to them (Shaibu 2006, 93). This poses a problem when household caregivers have not been properly trained, putting them at greater risk of contracting the disease. Lindsey et al. (2003) found that some family members refused to wear protective clothing such as gloves, believing that this created an unacceptable barrier between themselves and their sick family member. One mother said, “It is my daughter, I love her. I can’t wear gloves or other things. If I am holding or nursing my child I love, putting a barrier would be like I don’t love her” (495).

Lack of Transportation

Lack of transportation hinders visitation and supervision of CHBC services. In Shaibu’s study (2006) in Mmopane village, CHBC volunteers explained that having no vehicle meant that patients living in remote areas could not be easily reached and therefore did not receive as many visitations (92). Other programs fortunate enough to own a vehicle reported that lack of money for gasoline drivers resulted in ineffective use of the vehicle (Interview C 2008). The situation is also worse in rural areas, where roads are poor and sometimes impassable during rainy seasons (Odek and Oloo 2007, 11). In a case study of a CHBC program in Palapye, there was only one vehicle available for nurses, placing an extra physical demand on them as they were forced to walk long distances in the heat to reach their patients (HDN 2001, 34).

Disjointed Referral Systems

There is a clear lack of coordination from referral hospitals to CHBC committees. In Mmopane village, Shaibu (2006) observed that there was no network of resources and services that

ensured the continuity of care as patients move back and forth between health services. One CHBC nurse noted, “In my district there is a huge gap between being discharged from the hospital and the CHBC team being informed due to administrative problems and delays” (92). This weak liaison between hospitals and CHBC programs results in inadequate assessments of patients’ home environments when they are referred home to be cared for. In many instances, CHBC team members are the ones entering the community to find patients needing their services, rather than these people being referred to their services through the hospital (Interview B 2008). The provision of home-based care is supposed to be a complement to the work of local health clinics, so that when patients need clinical care there are appropriate referrals in place. The lack of effective linkages makes the process of bringing a CHBC client to a clinic more time-consuming and difficult (Interview C 2008).

Inadequate Support for Caregivers

Providing care to HIV/AIDS patients is demanding and exhausting work. Trained volunteers and nurses are few, and many are severely overworked. Caregivers often express feelings of guilt, helplessness, anger, and alienation. Witnessing death is emotionally draining, yet no counseling programs are in place to assist them, causing many to seek help on their own from outside support sources (Odek and Oloo 2007, 10). A CHBC nurse working in Old Naledi stated,

I get depressed. Caring makes you stay in constant emotional pain. I am always praying to God for a cure of healing. I am always tired. Sometimes I can’t even wake up to help her [the patient]. I really need more help. Your spirits become too low because we see too many young people dying... (Lindsey et al. 2003, 495-496)

These stresses increase the risk of burnout, with many caregivers leaving to find other work, making it difficult for CHBC programs to recruit and retain staff (Interview B 2008).

Lack of Support for Palliative Care

Palliative care, which embraces a combination of therapies and treatments with special focus on pain relief and symptom management, is often neglected in the provision of care and support to HIV/AIDS patients in Botswana. All of the directors of CHBC organizations that were interviewed reported a lack of understanding of palliative care among caregivers and an inadequate capacity to train for it (Interview A 2008; Interview B 2008; Interview C 2008). Although the philosophy of CHBC includes palliative care, many programs have had difficulty accessing and administering these services. Currently, there are no country-specific guidelines on palliative care in Botswana, making it difficult to receive government funding for improving these services (APCA 2005, 18). The director of Holy Cross Hospice stated:

Our volunteers have limited or no skills training in palliative care and this is because this type of skills training is not available or easily accessible. We cannot afford to bring in trained professionals, so really it is up to the government to incorporate palliative care into the national health policy (Interview B 2008).

The introduction of free, government sponsored ARV therapy in 2001 has slightly changed the face of home based care in Botswana—shifting from an emphasis of end-of-life care to teaching patients “how to live positively with AIDS” and rehabilitating them back into good health and work force. While ARV treatment has been an important step, some express concern that this program could further diminish interest in supporting the further development and expansion of palliative care in Botswana (Ogden et al. 2004, 33).

VI. Recommendations

The findings of this study bring me back to the fundamental question: Does CHBC for HIV/AIDS patients ultimately relieve or worsen human suffering? Are the challenges outlined in this paper simply too great to make CHBC an effective form of care in Botswana?

The answer to these questions are not simple. There is no question that hardworking caregivers in existing programs are making a difference in the lives of their clients. In the Kgatleng district, for example, caregivers were optimistic about the impact of their work and believed that they played a very important role for their clients, who trust and have confidence in them and appreciate having a person to share their questions and fears (Buwalda and Kruijthoff 1994, 7). Nevertheless, there remain significant obstacles to the long-term success of CHBC programs that policy-makers and the government must take seriously.

The following recommendations would strengthen existing CHBC programs and could pave the way for success in the long run: (1) Development of income-generating activities and food security initiatives to underpin household stability and well-being; (2) Greater allocation of government funds to CHBC services to address such fundamental problems as lack of transportation; (3) Implementation of educational programs to demystify HIV/AIDS, with the goal of alleviating the fear and stigma associated with the disease; (4) Closer collaboration with household members, through educational interventions regarding caregiving, safety, and decreasing the burden of caregiving on women; (5) Strengthening referral networks between formal health services and CHBC programs; (6) Provision of additional psychosocial and emotional support for caregivers; (7) Integration of palliative care program into the national health plan; and (8) Conducting annual evaluations of CHBC programs to assess resource needs and ensure program sustainability.

Some of these reforms may already be underway.. For example, Otse Home Based Care has initiated several income-generating projects, including a jewelry making workshop, sewing knitting and crocheting workshops, and a labor group focused on small-scale agricultural production, which have served to improve the economic well-being of households (Setso Project 2008). More collaboration between CHBC organizations within Botswana would help to attain specific goals, such as improving household security, and communicate ways these small successes can be replicated. Additionally, a Palliative Care Strategy was launched by the Ministry of Health in June 2005, with Shelia Tlou stating “those who have reached a dying stage should not die in pain and loss of control of their dignity in an era where we can provide palliative care” (BOPA 2005). Currently the program has started the training of twenty people in palliative care for CHBC patients. These are indeed steps in the right direction.

VII. Conclusion: Bringing HIV/AIDS Care Home

Care in the home, and caring for the household and the carers in the household is important because the worst impacts are felt in households and clusters of households. It is here that costs of the disease are borne. It is here that the mitigation interventions have to be located if they are to be effective and sustainable. It is here that social reproduction occurs at its deepest level: in the stories told by parents and grandparents to their children, in the giving and receiving of affection, in the taking and relinquishing of responsibility. It is also here that the government and international community have most difficulty responding. (Barnett and Whiteside 2002, 14-15)

As illustrated by Barnett and Whiteside (2002), the home is a very important environment for care, but it is also a setting in which serious challenges arise. It is clear that these challenges are multifaceted and cannot be solved in isolation. When the former Minister of Health, Joy Phumapahi, declares that home-based care should be a cornerstone of the AIDS strategy, then this calls for a truly holistic and comprehensive care agenda. Clearly NGOs cannot forward such an

agenda alone; the government of Botswana needs to do more in providing leadership as well as financial and administrative support.

If HIV/AIDS care is to be provided in the home, it is of utmost importance to address the needs of households and ensure they have the basic necessities that are required in order to provide quality care. Ultimately, the success of these programs comes down to availability of sufficient resources, combined with their effective implementation. Relatives and friends are fundamentally valuable resources in times of need, yet it is critical that families as the sources of care not be exploited. As Seeley et al. (1993) states, “blanket statements about the role of the extended family in Africa as a safety net need to be questioned and assumptions that the extended family will be ready and able to assist sick members, treated with caution” (quoted in Ogden et al. 2004, 16). Families can certainly be instrumental in providing care and support, but they cannot do it alone. They need effective partnerships and real, determined leadership from political leaders at the local, regional, and national levels. Only this kind of serious, sustained level of concentrated and coordinated effort holds the promise of improving and strengthening community home-based care programs in Botswana.

VIII. Further Research

Further research that could ensue from this study include learning more about CHBC patients' views of how and whether these programs are reflecting their felt needs, applying a cost analysis to programs to determine their current cost efficiency and potential for expansion and scale-up, and investigating the availability and access to ARV treatment in CHBC programs. It is important also to examine the role of traditional medicine in home-based care and how these programs are accommodating orphans and other children made vulnerable by HIV/AIDS. Further investigation of successful CHBC programs that have been implemented in southern

Africa will help to develop more concrete and detailed steps in achieving the recommendations put forth in this study.

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Interviews

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