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**The Impact of Government Support to
Community AIDS Home-Based Care
Delivery**



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1. Introduction

Since Botswana gained independence in 1966, she has enjoyed steady economic growth and graduated from being one of the poorest countries in the world. Botswana is now among the few African countries classified as “Upper Middle Income.”

Not only has economic growth been rapid, but progress in the development of infrastructure and improvement in social indicators in the past 20 years has been impressive. The economic growth and social development indicators in Botswana compare favourably with those of other countries in Sub-Saharan Africa. (Ministry of Finance and Development Planning, 1997). However, these achievements are being seriously undermined by the impact of the AIDS epidemic. UNAIDS (2000) estimates that Sub-Saharan Africa alone has 24.5 million adults and children living with HIV/AIDS. Botswana is among the top five hardest hit countries with 35.8% of adults infected with HIV. This is a real catastrophe for a country with a population of only 1.6 million and if such infection rates continue, Vision 2016 will be but a dream (Prof. S. Tlou, 2000).

Although Botswana has an enviable track record with respect to its leading macroeconomic and social indicators in the region, poverty still remains a major problem and a political challenge. The impact of the AIDS epidemic is mostly felt by poorer households whose AIDS patients are more prone to opportunistic infections due to poor nutritional status and rough living conditions. This situation is made worse by the fact that, the most affected cohort of the population is the economically active and this will reduce the level of food security at the household level.

1.1 Statement of the problem

The HIV/AIDS pandemic is already having a major impact on the quality of life in Botswana and has put a strain on the public health care facilities. Community-based care activities, such as home-based care and counseling, are, among others, intended to facilitate the process of reducing the emotional stress on AIDS patients, their care givers at home and the orphans. Therefore, when one talks about AIDS home-based care initiatives by the communities, one cannot leave out the issue of orphans. Very often they have volunteer care givers as their only source of hope for gaining access to social welfare programmes once their parents have passed away. The care givers are usually the first in line in the process of identifying orphans and linking them with

the Social Welfare Department. The Botswana Government has acknowledged the significant role of community-based interventions in the care of AIDS patients and orphans to the extent that lessons learnt from some of the pilot projects were used to inform the further development of a national home-based care programme.

Some of the key areas challenging the sustainability of these community initiatives are the lack of incentives for care-givers, the poor nutritional status of the AIDS patients due to poverty and the plight of orphans from poor households. Recent studies and reports conducted on the situation of orphans indicate that orphans have no adequate access to basic needs. Provision of basic needs of food, clothing, toiletry and shelter are the most urgent and immediate needs for orphans in Botswana. In response to this situation, the Ministry of Local Government, through its Division of Social Welfare came up with schemes that are targeting People Living With AIDS (PLWA) and orphans. Orphan support by Government is still to be properly defined. Such support is currently based on the recommendations contained in the *Short Term Plan of Action on care of Orphans in Botswana – 1999-2001*. Support to PLWA is based on guidelines for food baskets developed by the Ministry of Local Government. The same Ministry is responsible for the issuing of the P100/month incentive for volunteer care-givers. Other incentives for care-givers such as, uniforms, come from the Ministry of Health.

The good intentions of Government in supporting community-based initiatives for the care of those affected by AIDS are marred by a variety of problems including:

- Lack of a reliable database for needy orphans (who are they and where can they be found?). The concept of registering AIDS orphans began in 1996 in the Bobirwa area through the community home-based care project in the four villages of Bobonong, Sefophe, Tsetsejwe and Mmadinare. The quality of life of the orphans remains a concern, even after they receive Government support;
- Confusion in interpreting Government policy or guidelines governing the issuing of food baskets for people on home-based care. The policy does not require testing of patients before they can receive the food basket. But, in some cases, social workers insist on a test being taken in order for patients to qualify for the food basket. The author had first hand experience of this situation in 2000, whereby a

critically ill patient in Molepolole was not receiving any support pending the outcome of the HIV test imposed by social workers.

- With regards to care-givers' allowance of P100/ month, there was evidence in Molepolole that the number of volunteers increased once the allowance was introduced. The issue of concern here is whether or not the new volunteers could cope with the emotionally involving activity of caring for the terminally ill. How did the introduction of this incentive change the group dynamics of the care-givers? There is also the issue of monitoring of the payment of the allowance. Are registers of home visits strictly kept? Or does it suffice for a volunteer to register, attend a few meetings and make a few visits in a month in order to qualify for the allowance? Officers from the Social Welfare Department in the Ministry of Local Government indicated that the budget allocated for care-giver allowances is not sufficient to pay all the volunteers. In some cases, care-givers had to be paid on a rotational basis. This approach is likely to disrupt the composition of the groups to the detriment of the patients and orphans.

1.2 Government's response to the epidemic

The first case of AIDS was officially reported in 1985 and Botswana is now counted as one of the countries with a high prevalence of HIV AIDS in Sub-Saharan Africa and indeed in the world. According to information from the Ministry of Health, government responded to the epidemic as follows:

In 1986, the government set up a programme under the Epidemiology Unit of the Ministry of Health. The major focus of this programme was to screen blood products and to ensure the supply and use of disposable needles throughout the National Health Services. Meanwhile, the Government invited The World Health Organisation (WHO) to provide technical assistance to develop a National AIDS Control Programme (NACP). This programme resulted in the creation of an emergency Short Term Plan (STP) in 1987 for the period 1987-1989. The STP focused on increasing national public awareness of HIV and on training health workers in AIDS clinical management. This emergency plan was followed by the first five year Medium Term Plan (MTP 1) covering 1989-1993. The MTP 1 strategies were:

- strengthening epidemiological surveillance activities;
- prevention of sexual transmission of HIV;
- prevention of HIV transmission through blood and blood products;

- prevention of prenatal transmission;
- strengthening diagnostic management and infection control; and
- setting up systems for monitoring and evaluation

(Ministry of Health, 1997).

In 1992, the AIDS/Sexually Transmitted Disease (STD) Unit was established to coordinate the National AIDS Control Programme. The unit was created as a separate entity from the Epidemiology Unit where the NACP was initially located. The creation of the AIDS/STD unit was a merger between two formerly independent programmes, the NACP and the STD programmes. The unit operates through four sub-units of, Counseling and Home-Based Care; Information, Education and Communication/IEC; Surveillance and the STD sub-unit.

Additional measures were also taken when in 1993. A National AIDS Policy was prepared and adopted through a Presidential Directive. The policy provides a guide and a framework for a National Multi-sectoral response to the HIV/AIDS epidemic (Districts now have Multi-Sectoral AIDS committees chaired by District Commissioners).

Building on experiences gained from the implementation of the MTP 1, the process of preparing the MTP 2 began in 1994. This was a thorough and often painstaking process of participatory planning with all stakeholders, such as NGOs, the private sector and the nation at large. The MTP 2 covers the period 1997 – 2002, and its main goals are to reduce HIV infection and transmission and to reduce the impact of HIV and AIDS at all levels of society in Botswana. In operational terms, the main thrust of MTP 2 is its advocacy for the multi-sectoral approach, each District is to set up a committee which will coordinate and monitor all AIDS related activities within its boundaries. The MTP2 goal of reducing the transmission of HIV infection is in line with Vision 2016 which has this to say about the AIDS pandemic: *“There is a major challenge to halt or reverse the rising incidence of the HIV virus, particularly amongst young people, if Botswana is to advance in the next twenty years and beyond”* (Vision 2016, page 25).

Because the AIDS/STD Unit became overwhelmed with responsibilities and was plagued by manpower and other resource shortages, Government took another

proactive step and appointed the National AIDS Coordinating Agency (NACA) in 2000, headed by a Coordinator at the Permanent Secretary level. The main responsibility of NACA is to coordinate and monitor the national response to the AIDS epidemic by both Government, civil society and the private sector. The National AIDS Council is chaired by His Excellency the President. These are some of the significant steps taken by Government to consolidate its response to the AIDS crisis.

1.3 The development of a home-based care programme in Botswana

In spite of all the actions undertaken by government and members of the civil society, such as NGOs, to combat the spread of AIDS, the situation continues to deteriorate. The available health facilities cannot cope with the ever-increasing numbers of AIDS patients who spend long periods of time in hospitals without any hope of being cured. These patients have to give up bed spaces to those patients with curable diseases because not much can really be done for them. This situation renders home-based care a necessity. According to the Ministry of Health (1999), the global objectives of HBC in Botswana are;

- to provide optimal care for the chronically and terminally ill patients;
- to provide appropriate clinical and nursing care for patients at home;
- to provide counselling and social support services to patients within their home environment;
- to increase the level of HIV/AIDS awareness in the community.

Action towards developing a HBC system in Botswana only started in 1994 with a feasibility study undertaken with the help of the World Bank. In 1995, two pilot sites were selected, namely Tutume and Molepolole. Training for HBC staff was done for officers from the pilot villages and an awareness creation campaign was undertaken. The piloting did not last long enough to yield results that could adequately inform policy formulation because as soon as the year long piloting period lapsed, no follow up was done and the momentum and interest that had been created within the communities was subsequently lost. One other major step towards building a HBC programme by the Ministry of Health was the production of operational guidelines which could guide districts and any other organisation that had plans to embark on this task. Although grossly understaffed, the HBC section of the AIDS/STD Unit also

has the responsibility to give operational and professional support to all Districts on setting up and running HBC programmes. This support is extended to NGOs and community-based groups.

1.3 Literature Review on AIDS Home Based Care interventions

Russell Kerkhoven (1997) describes various models of home-care during the initial phase of the epidemic, which are related to their institutional base, as follows:

The hospital outreach model, which generally refers to a care team that goes out into the community to provide care within a home setting. These teams are often multi-disciplinary, involving community nurses, counsellors, nutritionists and even medical doctors. To varying degrees, the teams are well equipped with medical kits, linen and other means of assistance, such as food. This approach is rarely seen now, the high operational costs obviously affect the medium to long term sustainability of this initial approach.

The NGO outreach model, sought to bridge the gap between the hospital or clinic and community. The NGO identified its role as a facilitator or initiator of assisting the community to provide care for sick members – a service focused model. Care should be taken, when talking about NGOs, in order not to automatically assume that such organizations are community-based. Depending on the capacity of the NGO, there would be a coordinator, and home visits would be undertaken as per a schedule or based on criteria such as availability of staff, transport or medical care needs. The NGOs were quick to learn that the need in the communities was increasing dramatically over time and that some form of community involvement was essential. This led to the involvement of some volunteers who pay visits and provide assistance to sick members of the community. In Sub-Saharan Africa, there are a number of examples of this type of service that are making a noteworthy impact on the provision of care.

The community model, is the organization of care and support services for clients organized by the community. The type and quality of services varies considerably. In some cases, the support consists only of prayer meetings in the home that offer patients moral support; other models offer nursing care, basic counseling services and

training family members in care provision (this is the model commonly found in Botswana). Areas of concern in this model include the frequency of visits due to logistical constraints and the fact that the needs of particular households such as, clothing and shelter might not be met by the services provided. The effectiveness of this type of scheme depends on the existence and strength of community structures that have been brought to recruit the volunteers (like the Kgotla system in Botswana), the delivery of services and the provision of care. Indeed, the forerunners of these models in Botswana are mostly found in rural villages, as opposed to urban centers where community ties are much weaker.

In recent years, there has been a development towards an integrated model that combines community involvement, NGO participation and support links with hospitals or clinics. This has been captured in the phrase "continuum of care." It allows for the identification of different entry points in order to access the appropriate type of care.

The concept of continuum of care continues to be poorly misunderstood by many involved in both regular and informal health and social care activities. Consequently, the available community and hospital resources have continued to operate independently and, at times, in competition with each other. Community based care as part of a continuum can reduce the cost of institutional health care and improve the quality of life of PLWA and their families. Recent home-care studies showed that the cost of an outreach visit varied, e.g. US\$16 (Zambia), US\$42 (Zimbabwe) and US\$49 (Botswana). Hospital outreach services are costly compared to community based care models. Moreover, the bulk of expenditures goes to costs such as transport and staff salaries, which are of no direct benefit to the patients. From recent reviews in Botswana, Cote d'Ivoire, Kenya, Tanzania, Uganda, Zambia and Zimbabwe, between 20-200 care projects are operating in the respective countries, with each project visiting up to a few affected families in a given year. (Osborne et al. 1997). In Botswana, community care givers make frequent visits of about three visits per week to their patients. Nthutang (1999) in her study of the effectiveness of the Gabane home-based care committee, is of the view that the group was effective because patients preferred home care to hospitalisation.

The care burden, particularly in African countries hard hit by the AIDS pandemic, is already heavy. To quantify the financial costs attributed to HIV/AIDS to the health system and to families is difficult. The World Bank calculates that, if all AIDS patients in Tanzania were treated in public health facilities, and if sufficient essential drugs were available for this purpose, treatment would absorb roughly half of the country's entire public health recurrent budget for that year. (R. Danziger, 1994).

1.4 Needs for care and support

In recent years, several studies have been done to increase understanding of the needs of families living with HIV/AIDS and how these families differ from those of similar families which are not directly affected. Studies in Malawi, Uganda, Zimbabwe and Kenya reveal a similar picture of needs, mainly expressed in four areas: food, clothing, medicines and support for surviving children (van Praag et al. 1997). The continued schooling for surviving children is of great concern. Often, when one or both parents are ill, a child (mostly the girl-child) is taken out of school due to dwindling income and need for help with household chores. Provision of school fees and uniform is a commonly expressed need since schooling is seen as the only hope for a brighter future.

Van Praag views the lack of efficient use of available resources as a potential problem, and maintains that accountability is thus another important requirement in community-based initiatives. In the Botswana situation, this accountability should be sought mainly from public officers from the Ministry of Health and Local Government who have the responsibility to give support to people living with AIDS, care givers and AIDS orphans.

2. Objectives

- To explore the impact of Government support to community home-based care activities.
- The study would also look at whether or not the Government has any mechanisms in place to monitor the impact of this kind of support in order to inform the way forward.

3. Hypothesis

Government support to community home-based care initiatives has not had the desired impact of motivating care givers and that;

Government attempt to improving the welfare of AIDS patients on home-care and orphans has also not had the desired impact.

4.0 Methodology

A variety of data collection methods will be used in the study; structured interviews using a questionnaire, focus group discussions with care givers, review of records of care givers to get information like orphan registration and others. Structured interviews define situations in advance and attempt to get answers to them. Focus group discussions on the other hand will provide the researcher with the opportunity to probe deeply into the subject matter and uncover new clues. The main unit of analysis will be the home based-care groups who are the key custodians of much of the information under review.

Senior officers in the Ministries of Health and Local Government will be interviewed in relation to the implementation of the Short Term Plan of Action on Care Of Orphans (1999-2001) and regarding the issue of eligibility of food baskets for PLWA. Social and Community Development Officers at the District Councils, who are working closely with the volunteer care givers, will be another source of valuable information regarding their understanding of, and role in deciding who qualifies for the prescribed food basket for AIDS patients on home based care.

If evidence emerges to the effect that over 50% of all the AIDS patients under the care of the selected home-based care groups, and registered orphans, are getting Government support, then the policy of Government to support them will have had the desired impact and the hypothesis will be disproved. On the other hand, if less than 50% of the registered orphans and AIDS patients on home-based care still do not receive the support that Government has pledged to give them, the schemes in place will not have had the intended impact. The researcher will then come up with ways in which the situation could be improved based on information gathered from the various respondents.

There are many communities involved in AIDS home-based care and the choice of a research site is based on convenience for the researcher. Molepolole has over 10 community home-based care groups which would offer an adequate sample. Furthermore, the researcher has had contact with that particular project previously from her former job as Programme Officer for the Netherlands Development Organisation and during the period of data collection for Botswana's Human Development Report 2000 last year. Some of the questions to be answered in the study emerged during that exercise.

5. Work plan and time frame

The project is to be carried out in various (over lapping) stages as illustrated in the table below.

Stage\Time	March	Month 2	Month 3	Month 4
Proposal	██████████			
Data collection	████████████████████			
Draft Report		██████████████████		
Final Report			██████████████████	

6. Budget

	Unit	Quantity	Unit Cost/day (Pula)	Totals (P)
Fees				
Researcher	Mandays	40	950.00	38,000.00
Sub-total				
Transport	km	250	1.07	267.50
Sub-total				
Miscellaneous (tel., stationery etc.)			250.00	250.00
Sub-total				
Total				38,517.00
Contingency (10%)				3851.75
Grand Total				42,368.75

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