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CHALLENGES FACING COMMUNITY HOME-BASED CARE PROGRAMMES IN BOTSWANA

Antony W. Odek[*] and *James A. Oloo*[**]

Abstract: This study examines the role of Community Home-Based Care in Botswana for people with HIV/AIDS and those with other terminal illnesses. Kerkhoven and Jackson (1995) attribute the popularity of Community Home-Based Care (CHBC) programmes in the developing countries to high rates of HIV/AIDS. Botswana has adult HIV/AIDS prevalence rate of 37 per cent and over 350,000 people living with HIV/AIDS. Rapid rise in incidences of HIV/AIDS has hence resulted in increasing need for CHBC and thus many CHBC services have been established through disorganized and fragmented manners. This paper is an extended literature review. It identifies and discusses challenges facing CHBC programmes in Botswana. The findings indicate that poverty, high cost of community care, inadequate medical facilities, poor infrastructures and socio-cultural issues have threatened the sustainability of CHBC programmes in Botswana. Recommendations and policy options are discussed.

Key words: Home-based care, HIV/AIDS patients, challenges, socio-cultural, Botswana

1. BACKGROUND

With HIV/AIDS prevalence rate of 37 per cent, Botswana is one of the countries worst affected by the disease (Central Intelligence Agency 2006). The mounting morbidity and mortality of HIV/AIDS has placed an increasing demand on the already overburdened health services. For example, Botswana has just over 40 medical doctors for every 100,000 people (SIDA 2006).

The burden of caring for the ill has thus moved to the community and the family. Communities have responded to this need by developing community home-based Care programmes to support friends and relatives

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in need (Kerkhoven and Jackson 1995). Providing care to terminally ill relatives places a lot of stress on the family in terms of labour, finance and emotional strain (Jackson 2002). Primary caregivers, who are most likely to be women and girls, bear the physical, psychological and financial burdens on their health, such as forgone earnings or being pulled out of school, risk of infection, stigma, and the knowledge that the ill relative will die (Kerkhoven and Jackson 1995).

HIV/AIDS has a substantially negative impact on African health centres, including Botswana's health sector. As the epidemic matures, the demand for care for those living with HIV/AIDS rises, as does the toll among health workers and family members. For example, in 2000, about one half of beds in some health care centres and hospitals in Swaziland were occupied by HIV/AIDS patients. In Lesotho, more than 34 per cent of hospitalized patients in one hospital were people living with HIV, making HIV a major cause of illness leading to hospitalization. The impact of HIV/AIDS on households needs no overemphasis. It is often the poor that are most vulnerable and get hit the hardest. In many cases, the family looses its assets and livelihood before it eventually disintegrates as parents die and children are raised by relatives or live in the streets.

In Botswana, household income for the poorest quarter of households is expected to fall by 13 per cent between 2000 and 2015. Income earners in these households are also expected to take on an average of four more dependants because of HIV/AIDS (Cohen ND). It is estimated that in Kenya, 17 per cent of rural families have reduced their agricultural work due to HIV/AIDS. In Ethiopia, AIDS-affected households were found to spend 11-16 hours per week performing agricultural work, compared with an average 33 hours for non-AIDS affected households (AVERT 2006). Yet, with a median age of less than 20 years, the future looks bleak unless the spread of the epidemic is arrested (Central Intelligence Agency 2006).

A significant response of people living with or affected by HIV/AIDS has been to form a diversity of self-help CHBC programmes. The term CHBC was originally used to refer to a programme that offers health services to support an ailing person (WHO 1999). The World Health Organisation (2001) views CHBC as the care given to the terminally ill in their home, usually by their relatives and supported by skilled health care providers. However, the meaning of the CHBC has expanded to include full range of services and settings available to terminally or critically ill people in their own homes. The programme is viewed as an initiative whose implementation depends on human and infrastructure capacity of a region. The effectiveness of CHBC will depend on the efforts made to prepare and support health care workers, nurses, doctors, clinical officers and People Living with AIDS (PLWAs). The CHBC initiative aims at increasing service utilization and Antiretroviral (ARV) adherence through supporting community-driven responses to the pandemic of HIV/AIDS. It emphasizes

activities which contribute to care and support for people who are infected and affected. Some of the services given priority in CHBC include counselling, income generating activities, training of volunteers on quality home-based care, and financial support for access to ARVs. Such activities are in line with the Multisectoral Plan to Fight HIV/AIDS implementation manual in a number of countries.

2. STATEMENT OF THE PROBLEM

Despite the existence of CHBC programmes in Botswana, for now, almost a decade, not much in-depth critical analysis of the challenges facing it has been undertaken (Mathebula 2000). This study was designed with this gap in mind. Through it we hope to increase the level of understanding of the major bottlenecks facing the implementation of the CHBC programme in Botswana and make possible recommendations that lead to the strengthening of the programme.

3. OBJECTIVES OF THE STUDY

This paper sought to assess challenges facing successful implementation of CHBC programmes in Botswana. The study is important in two main ways. First, it is a contribution to existing theoretical knowledge about CHBC in Botswana, and second, it is an attempt to contribute to knowledge in this field, motivate further research, as well as inform policy decisions.

4. LITERATURE REVIEW

Both published and unpublished studies, as well as government documents and media reports were reviewed. A potential weakness of the reviews is that there are few reports and studies focusing on Botswana and thus an in-depth critique of the studies was not possible. Rather, the literature available helped inform this study on what has been done and the gaps that exist. Also, because until the emergence of HIV/AIDS in Botswana, few infectious diseases necessitated the need for CHBC, this study tends to talk more about HIV/AIDS than other terminal illnesses such as cancer. HIV/AIDS pandemic is now one of the most costly crises the world has ever experienced. For instance, it is estimated that by 2007 the world will need US$ 20 billion to provide antiretroviral treatment, support HIV/AIDS orphans, as well as provide HIV testing and counselling, and school-based HIV/AIDS education. About 43 per cent of these resources will be needed in sub-Saharan Africa (UNAIDS 2004).

Because of the current economic environment of reduced government spending on health care (under such International Monetary Fund and World Bank initiated Structural Adjustment Programmes), macro-economic adjustment outcomes in most parts of Africa have particularly affected marginalized groups (women, children and the poor) (Afshar and Dennis 1992). Inequities in access (between social classes and rural-urban divide)

to health care are widening, health services are decaying, and health is declining (Loewenson 1993; Robson 2000). Lack of easily accessible state provision, coupled with increasing health complications due to HIV/AIDS, has resulted in low-income households increasingly depending on informal and community/ home-based health care (Ogden and Kyomuhendo 1996).

Upon the introduction of SAP in African countries, among them Botswana, between late 1980s and mid-1990s, the use of home treatments increased; fewer ill people could afford government health services, and attendance at health care facilities declined (Bassett, Bijlmakers and Sanders 1997; Robson 2000). However, community home-based care programmes in Botswana remain under-researched.

CHBC initiative is common worldwide. In Senegal, the AIDS Care Team's goal is to provide solid recommendations to the government on how best to improve HIV and AIDS care on a national level. Based on the findings of the Senegalese Team, the government decided to launch campaigns on consistent treatment and appropriate guidelines for opportunistic infections to the terminally ill. In Zambia, people living with Aids have benefited from the creation of a continuation of care through the forging of links between patients, their homes, health centres and district hospitals. Monze District hospital in Zambia has developed a community outreach programme, including a strong element of support for patients and caregivers in their homes, while the Salvation Army Chikankata Hospital Project provides accommodation in the form of traditional houses in the hospital grounds for families of patients so that they can participate in care giving (ACTION AID 1990).

Botswana's response to the HIV/AIDS epidemic can be divided into three stages. The early stage (1987-89) focused mainly on the screening of blood to eliminate the risk of HIV transmission through blood transfusion. The second stage (1989-97), and the first Medium Term Plan (MTP), saw the introduction of information, education and communication programmes. The response was, however, criticised for lacking in focus and implementation strategies. During this stage, the government adopted the Botswana National Policy on AIDS. In the third stage (1997-2002), MTP II was introduced which involved many stakeholders who had previously been excluded, with the overall aim, not only of reducing HIV infection and transmission, but also reducing the impact of HIV/AIDS at all levels of society. Under this programme, the effectiveness of CHBC could be influenced by efforts made to prepare and support health care workers, nurses, doctors, clinical officers and people living with HIV/AIDS (Odek 2004). The CHBC programmes would have to be tailored to the settings in which they are implemented.

5. METHODOLOGY AND DATA

To pursue the study objectives, a qualitative methodology was imperative, and was employed by conducting document studies and alternative assessment. Existing records (both academic studies and government records) provide insights into a setting and/or group of people that cannot be observed or noted in another way (Morse 1994). While this information was found in document form, the existing sources were accessible and fairly accurate.

Again; qualitative methodology was used because it is well suited to an exploratory study of a population about which 'little' is known for two main reasons: First, literature review provided an opportunity to gain insights into the socioeconomic dynamics of Botswana, particularly, the effect of HIV/AIDS. Second, it enabled the researchers to assess subtle interactions between individuals and societal behaviours within the larger social context (Oloo 2005).

The usefulness of existing sources varies depending on their accessibility and accuracy. In the hypothetical project, documents can provide the evaluator with useful information about the culture of the institution and participants involved in the project, which, in turn, can assist in the development of evaluation questions. Information from documents also can be helpful to generate interview questions or to identify events to be observed. Furthermore, existing records can be helpful for making comparisons (e.g. comparing project participants to project applicants, project proposals to implementation records, or documentation of institutional policies and programme descriptions prior to and following implementation of project interventions and activities) (Debus 1995).

As well, the methodology adopted is important because it was locally available, inexpensive, and was grounded in the setting and languages in which they occur, and provided the opportunity to study trends over time. However, potential weakness of this methodology is that the documents could be inaccurate or of questionable authenticity, incomplete, as locating suitable documents may pose challenges (Denzin and Lincoln 1994).

5.1 Research Design

Leedy and Ormrod (1985) view research design as a detailed plan of how a study is conducted. This study is a research essay based on an extensive literature review gathered from different sources. Anderson (1998) posits that successful research is based on knowledge, research and thinking that precedes it. Hence, literature review is a research activity in its own right as it "involves many of the same steps of doing original research" (Anderson 1998, 77). This design is useful in a situation where secondary data sources are accessible as was the case in the present study. The data were collected from Botswana Archives, Ministry of Health/ STD Unit, and NGOs that deal with CHBC programmes, University of Botswana Library, as well as

other print and electronic databases. A potential weakness of this study is that it relies primarily on literature review while excluding vital primary data.

5.2 The Study Site

This study was conducted in Botswana. There are around 60,000 registered HIV/AIDS orphans in the country. The figure is likely to increase to about 200,000 orphans by 2010 if the current situation is not reversed (Gapathuse 2003), as average life expectancy in Botswana falls from the current 74 years to about 27 years by 2010 (see Table 1).

Table 1. Distribution of average life expectancy in some African countries, by years

Country	Age in years before HIV/AIDS	Age in years by 2010
Angola	41.3	35.0
Botswana	74.4	26.7
Lesotho	67.2	36.5
Malawi	69.4	36.9
Mozambique	42.5	27.1
Namibia	68.8	33.8
South Africa	68.5	36.5
Swaziland	74.6	33.0
Zambia	68.6	34.4
Zimbabwe	71.4	34.6

SOURCE: Stanecki (2002)

5.3 Data Analysis

Data was analysed and interpreted to meet the objectives of the study and to identify existing gaps in the CHBC programmes. Special attention was given to the effects of HIV/AIDS as a major driving factor on CHBC. Where possible, comparisons with other African countries are made. Recommendations and policy options are likewise briefly discussed.

6. COMMUNITY HOME-BASED CARE PROGRAMMES: AN OVERVIEW

Implementation of CHBC programmes is consistent with the care strategy recommended by the Botswana government for HIV/AIDS infected and

affected individuals (Osborne 1997). Evidence shows that CHBC programmes enable the patients to receive care in familiar and supportive environment; are likely to reduce medical expenditure especially if the patient is not hospitalized; could act as a way of creating community awareness about a disease; as well, CHBC programmes ensure that health system does not need the creation of extra services where resources are already limited. It thus, reduces hospital visits as more care giving responsibility is taken up by the community (WHO 1999).

6.1 CHBC Programme in Botswana

The development of CHBC began in 1990 and the first two pilot projects were launched in Tutume and Molepolole two years later (NACP 41 1995). At the end of June 2000, over 7000 people were on CHBC programme. The programme was guided by the National HIV/AIDS policy that was reviewed in 1998 to incorporate community home-based Care and the National HIV/AIDS Strategic Plan (MTP II) which was developed in 1997. The stated objectives of the Community Home-Based Care Programme are as follows:

a) To increase the access of AIDS-affected families to skilled medical care, counselling and support on a regular basis;

b) To equip families with more skills in caring for their family members who are affected by HIV/AIDS and other terminal illnesses; and

c) To increase the access of families with AIDS patients to home care supplies.

The rationale for the implementation of CHBC in Botswana was in recognition of fact that it is one of the most cost-effective ways of caring for people with terminal illnesses. This reasoning was based on the premises that:

i) In Botswana, the family is traditionally the caring unit in the society and therefore a programme built on it is likely to succeed;

ii) Studies by Fidzani and Attah (1996) found that terminally ill patients prefer to be cared for and die at home;

iii) Due to the fact that HIV/AIDS devastates family resources, there is need to provide well-planned social services through the CHBC programme; and

iv) Because of the stigma attached to HIV/AIDS, preparing the family and the community at large by training and getting them involved in caring for those who are terminally ill is very important.

6.2 Models of CHBC in Botswana

Some of the notable models of CHBC programmes in Botswana are the Clinic-Centred Model, the Hospice Model and the Integrated or Theoretical Model. The Clinic-Centred Model offers medical services to the terminal patient in health centres. The patients are given medical attention and complex cases are referred to District hospitals. An example of Clinic Centred Model is the Kgatleng Project which ensures that medical supplies and professional staff are available. Hospice Model offers a number of services with the aim of providing a holistic support to the terminally ill. These services are spiritual, social, physical and psychological in nature. The Hospice principles and practice also offer end of life support [euthanasia] to terminally ill and suffering patients to ensure peaceful death. Some examples of Hospice Model are the Holy Cross Hospice in Gaborone and the Bamalete Lutheran Hospice in Ramotswa and Tutume. Lastly, the Integrated or Theoretical Model follows the government approach and this includes offering moral and financials support to enhance community care (NACP 41 1995).

7. FINDINGS AND DISCUSSIONS

7.1 Findings

The study revealed that various challenges have prevented health care providers from offering quality care to those who are suffering from AIDS and other chronic illnesses. These challenges will be discussed as follows.

Weaknesses in the Multi-Sectoral Committees

In reviewing the literature, weaknesses prevailing in the multi-sectoral were found to be among the serious challenges facing CHBC programmes in Botswana. This phenomenon can be explained by the fact that the District Multi-sectoral Committees (DMSACs) response operates at district levels and their activities are co-coordinated centrally through the Ministry of Local Government. The committees' are made up of professionals, leaders, community representatives and youths, and their tasks are to help in implementing HIV/AIDS prevention, care and control strategies. The civil service has full time HIV/AIDS co-coordinators to assist sectors to coordinate, plan and implement sector responses, and monitor and evaluate the impacts of HIV/AIDS programmes. Many DMSACs have not been able to attract professionals. A number of professionals have kept away for fear of being caught up in wrangles within the committees. There is also a feeling by professionals that their views would not be taken seriously by the DMSACs. Further, lack of focus and poor planning has resulted in DMSACs' getting involved in uncoordinated programmes. In 2000, Northeast District was reportedly experiencing various problems such as lack of a co-coordinator, transport and suitable site for the centre (Khan and Stegling 2000).

Poverty

Poverty represented one of the serious challenges to quality of service in community care. Narayan *et al* (2000) argue that poverty is pain and that poor people suffer physical pain that comes from little food and long hours of work stemming from daily humiliation of dependency and powerlessness as well as moral pain from being forced to make difficult choices such as whether to use the scarce funds to save the life of an ill family member or to use those same funds to feed their children. Terminal illness can make people lose productive jobs, household and subsistence labour. This study concurs with a fining by Khan and Stegling (2000) that many ill individuals expressed fear that no one will take care of their children after they die.

Socio-cultural Issues

Based on the Mexico Declaration of the United Nations (1982), a project aimed at protecting the rights of the indigenous people was initiated. It understood culture to include: ways of life, traditions and beliefs, representations of health and disease, perceptions of life and death, sexual norms and practices, power and gender relations, family structures, languages and means of communication, as well as arts and creativity.

Phaladze (1999) observes that care giving usually involves several family- and extended family members and that this sometimes acts as ground of conflict. Thus, family support can be both a resource as well as a problem. This poses a potential challenge to community health care and may affect the quality of care in the CHBC programme. This observation supports the findings by Fidzani and Attah (1996), which reveal that 22 per cent of the caregivers in their study were of the opinion that the community members were hostile to the affected families. Moroka (2003) posits that HIV/AIDS alters the traditional equilibrium between social structures and orphans, thereby decreasing the ability of society to respond while simultaneously producing overwhelming numbers of orphans. Moroka further observes that HIV/AIDS does not represent a normal circumstance and that the social capital decreases as the patient continues ailing.

Stigmatization

UNAIDS (2000) defines stigma as an act of identifying, labelling or attributing undesirable qualities targeted towards those who are perceived as being "shamefully different" and deviant from the social norm. In Botswana, people associate HIV/AIDS with sex workers and sexual promiscuity. Hence, a number of people have declined to participate in the war against HIV/AIDS for example by getting tested for the virus (Herek 1990). Such negative discrimination has prevented many people from seeking information on reproductive health (see also Fidzani and Attah 1996).

Inadequate Health Knowledge

Concerns were raised about the problems that home carers experience in their work. Dealing with death was especially hard due to imminent demise of a loved one as well as the caregivers' own fears about death. This made it difficult for caregivers to educate the families they cared for on death. Psychosocial support was found deficient. They felt ignorant and afraid as they lacked the skills necessary to provide quality care. Feelings of guilt, helplessness, anger and alienation were expressed by caregivers. Further, there was a general lack of information on the patient's condition, progress and prognosis, which was very stressful.

It was, however, very clear that a multidisciplinary approach was essential for the success of CHBC projects. Family caregivers, if supported, are able to provide a very valuable service to the community.

Lack of Palliative Services

One of the vital services in caring for patients with terminal illnesses is palliative service. The World Health Organization (WHO 1999) defines Palliative Care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (Ibid, p. 2). According to WHO, palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help the family cope during the patient's illness and in their own bereavement; and uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.

The hospice and palliative care movement in Africa started in 1979 with the establishment of the first hospice programme, Island Hospice, in Harare, Zimbabwe. This programme and others that followed in South Africa, Kenya and Uganda were modelled on the principles of hospice care from the United Kingdom but focused on the provision of CHBC for patients and not on specialized in-patient facilities. With the advent of the HIV/AIDS epidemic, the programmes modified their services to meet the needs of the ever-increasing number of AIDS patients in their communities. Now, as part of providing interdisciplinary care to HIV/AIDS patients, these programmes have begun carrying out community development activities as part of their service models, including expanded services for AIDS orphans, day-care programme for hospice patients and children infected and affected by AIDS, and feeding schemes for patients and their families (Foundation for Hospices in Sub-Saharan Africa 2007).

Despite its strengths, the effectiveness of palliative care in Botswana has been hindered by a number of challenges. These include insufficient funding, inadequate human resources, as well as a lack of paediatric palliative care for the children (Sepulveda *et al.* 2003).

Transportation Problems

Transportation remains a major problem for most HIV/AIDS patients and their caregivers, which makes it difficult to access medical services in the hospitals. The situation was found especially difficult in rural areas where roads are often in poor state, usually impassable during rainy seasons. A number of CHBC programmes lack means of transportation and this has made it hard for the caregivers to cover vast areas.

7.2 Discussion

The study set out with the aim of identifying and analysing the challenges facing CHBC programmes in Botswana. On the question of weaknesses in the multi-sectoral committees, the study found that the planning process of DAMSACs start at the village level, gets collated at the sub-district level then transmitted to the District level for compilation into the District Master Plan that will be presented to and approved by the District Committee. The process is co-ordinated by the District Planning Officer (DPLO) with technical assistance from the Sectoral Ministries (Health, Education, Agriculture, Water and Community Development, Women and Children Affairs) (Fidzani and Attah 1996). A possible explanation for this is that at every level, approval for implementation is based on resource allocation required at that level. The implications of this is that the communities are able to decide and implement all the elements on their plan, and that they can mobilize resources for themselves. However, the study recognises the fact that those resources from more central levels are also based on the taxes that families pay hence contradicts the intended purposes of lowering the burden on the poverty stricken families. On a positive note, the DAMSACs concept ensures that the people have a voice that can be expressed through their own democratic structures. They cannot be ignored since they can get on with their own activities, and can withhold tax if there are no services or tangible returns. This enhances accountability and fairness.

Although there are organizations working on CHBC programmes, very little was found in the literature on the ability of such organizations to expand the CHBC activities countrywide. This is confirmed by Osborne (1997) who posits that CHBC initiative was based on the hope that organizations would form clinics, outreach care hospice and community-based care. This has proved to be a mirage for most organizations. Even the anticipated support that was expected to come from the social workers, nurses and spiritual leaders has been very minimal (Fidzani and Attah 1996). A strong relationship between inadequate funds and poverty has

been reported in the literature. Increased poverty level has been blamed for poor quality services within CHBC; it caused families to reduce their outlays on food, leading to malnutrition, and to cut back on payments for school fees and uniforms for their children, thereby resulting in dropouts and lower levels of education (UNAIDS/WHO 2002).

In this study, stigma as well as a lack of confidentiality was found to lead to lack of involvement of PLWAs in health care settings. This is supported by a number of studies that have revealed that insufficient information to caregivers has hindered community care (see Fidzani and Attah 1996). This finding is also in agreement with the findings by Stegling (2000) which reveal that in 1998, the training of caregivers was not one of the major issues raised by the caregivers, although they were worried about contracting illnesses due to their care giving work.

Feminization of care giving is another important finding that was captured by the study. This finding is consistent with Shaibu's (1997) which substantiates that several caregivers subscribe to the belief that the girl child contributed more to the care giving than the boy. She adds that the elderly- especially grandmothers caring for their sick adult children and orphaned grandchildren- are actively involved in care giving despite the fact that they may not be strong enough to cope with the difficult task. Caregivers are usually mothers, grandmothers, sisters and in some cases school-age girls.

Another issue that emerged from the study is the inability to control pain and offer other palliative services. A research finding by Sepulveda *et al*. (2003) observes that pain management and accessible and affordable drugs are vital services that should be part and parcel of CHBC programmes, and that financial support should be aimed at replacing the loss of income of both patient and family caregivers.

However, cost, ignorance and false belief amongst the society members were found to hinder availability of palliative care. This was confirmed by a pilot project conducted in Botswana and five other countries in 2001. The study found that less than one per cent of the population that die yearly in most of those countries had access to palliative care. In Botswana, among 92 terminally ill patients that were interviewed, about 64 per cent of them experienced a lot of pain, 59 per cent lacked adequate food, and 41 per cent lacked social support, while 36 per cent experienced financial difficulties. The study also revealed 36 per cent of the patients received support from the relatives, 24 per cent from government, and 27 per cent indicated that they could not cope with their situation (Sepulveda *et al*. 2003). Perhaps this is part of the reason why the Ugandan government has involved traditional healers in training and how to administer herbal drugs that can reduce pain and suffering on the patients life (Sepulveda *et al*. 2003).

Many CBHC projects do not have adequate means of transport and communication such as vehicles and telephones. This, coupled with

remoteness of some places, makes it difficult for families and CHBC programmes to ferry patients to the hospitals. Similar outcome was realized by Ebun's (2003) research that aimed at assessing the strengths and weaknesses of CHBC programmes in Uganda. His study found that less than 50 per cent of the programmes had indicators of efficiency (such as cost of care per visit, and cost of care per patient per year) (see also Hansen *et al.* 1998).

CHBC involves a lot of hidden costs, such as the forgone earnings by the unpaid caregivers. Hope (1999) in Zimbabwe found difficulties in identifying programmes with efficient and accurate records of the expenditures and the costs. In Zimbabwe, the highest cost was salaries at 39-59 per cent, followed by transport at 25-50 per cent and medication at up to five per cent. A possible explanation for this is that home care visits can cost significantly more than inpatient hospital care due to remoteness of some places. Hansen *et al.* (1998) found that the average costs of one home visit in the more costly of the rural schemes was equivalent to 2.7 inpatient days at district hospital, and of the least costly urban scheme the cost equated to one hospital day.

8. CONCLUSIONS AND RECOMMENDATIONS

CHBC programmes face a number of challenges. Most poor families cannot afford well-balanced meals and both real and opportunity costs associated with CHBC. Stigma associated with terminal illnesses such as HIV/AIDS prevents many from accessing medical services. An inadequate palliative service has made patients die in pain. Lack of congruence with the national level planning where sectoral plans are demanded, as well as lack of skills and tools among frontline personnel to play their role in care giving process are serious issues that should be addressed. Other challenges which have negative implications on the quality of services in community care include poor communication, hidden costs and feminisation of the care giving role.

This study views the challenges facing CHBC programmes as a multifaceted process that cannot be solved in isolation. Based on the findings of this study the following recommendations are offered.

The CHBC initiative is about reaching out to individuals and families to ensure that the long-term ill individuals receive care and support in their own environment. The programme must call upon all possible partners in order to pool scarce resources and establish a coordinated response to ensure quality services. This requires bringing together HIV/AIDS stakeholders that do not usually collaborate to ensure services in the community care.

In most cases participatory planning of DAMSACs is not uniformly practiced as a normal approach outside externally funded initiatives. This

requires an animation team with standardized tools and guidelines to promote harmonization at more central levels. Again, a lot of planned activities tend to be physical hence the villagers should be synthesised to thinking beyond physical to other vital interventions which may take less resources and have more rapid results. For instance a Village First Aid Kit should be managed by a well-trained VHW instead of a dispensary.

There is a need to establish a research-based organization that promotes community-based Farmer Field Schools for the production of organic food and cash crops. The farmer fields should target widows, widowers and the elderly who are keen to grow crops without expensive inputs.

There is need to conduct basic training on diseases, disability, gender, and culturally sensitive practices that address knowledge, attitude and skills of the society members. This will create greater understanding amongst families and communities. Similarly, there should be efforts to demystify HIV/AIDS in order to alleviate the fear associated with it and consequently to reduce its stigmatization. This should be the responsibility of the CHBC programmes.

It is crucial to highlight the magnitude and the implications of women's unpaid care work in terms of social and economic costs and benefits, both to themselves, their communities and the larger society. This can be done through the media with the aim to make people appreciate the role played by women in the society.

In regard with palliative services, health professionals should be given training in alleviating the psychological, emotional, and existential suffering that may accompany dying. By the same token, there is need to develop guidelines and training for palliative care. This should be specifically included in national guidelines for the clinical management of HIV/AIDS.

Finally, there is need to develop strategies to enhance a more effective provision of CHBC services. This should include in-service training, dissemination of documents, development of induction documents and programmes; as well as provision of mechanisms to support volunteers; to revisit a multi-sectoral approach, and to maintain caregiver programmes through training.

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