Effects of the AIDS epidemic and the Community Home-Based Care programme on the health of older Batswana

Henry A. Akinsola*

Department of Nursing Education, University of Botswana

Abstract

Several recent studies have focussed on the needs and problems of different demographic groups pertaining to the HIV/AIDS epidemic in Botswana. However, none has paid particular attention to the impact of the epidemic on older persons, with specific reference to the Community Home-Based Care (CHBC) programme. This paper examines the experience of older Batswana of the AIDS epidemic, briefly describes the nature of the CHBC programme, and critically examines the social-psychological, economic and health implications of the programme for older persons, with specific reference to their role as primary caregivers to persons with AIDS and AIDS orphans. The dynamics of problems of the CHBC programme are analysed and solutions to the problems are suggested.

Introduction

In African countries, problems experienced by socially disadvantaged groups, such as handicapped persons and older persons, are subjects of academic discussion and debate by politicians and the elite, but the problems receive scant attention in practice. Currently, in several African countries such as Kenya, Ghana and Nigeria, a common feature of large cities and peri-urban communities is a sizeable number of older men and women who are destitute, street beggars or street traders. In addition, in several refuse landfill sites, for example in Ibaban, Lagos, Nairobi and Gaborone, numerous older women and men daily engage in "commercial scavenging," to provide for their basic needs, particularly food, shelter and clothing, and to support family. The pathetic situation of these persons may be related to problems often associated with a rapid transition from a rural to an urban life-style in these countries, which often leads to a breakdown in the extended family system. Due to high rates of unemployment and inflation, children and grandchildren, who are traditionally regarded as sources of social security for elderly parents, are often faced with a socio-economic crisis in the cities and towns, which prevents them from fulfilling that role. Older persons are in fact sometimes breadwinners for an extended family which relies on their sparse income (Akinsola, 1999).

From a health viewpoint, despite an increase in the need and demand for health care by older persons, very few studies have paid specific attention to the health care problems of older persons in Africa (Kalache, 1986; Olubiyide, Hart & Gombe, 1991; McLigeyo, 1993). The care of older persons in African countries in general is still viewed as the responsibility of family, particularly female members. For example, in traditional Tswana society, the sick and the elderly are taken care of by women as part of their domestic chores (Kupe, 1993). To date, there is no strong indication that geriatric health care is being recognized in African countries as being important. The effects of the AIDS epidemic are likely to compound the problem of the health status and health care of older persons.

Several recent studies have focussed on the needs and problems of different demographic groups as a result of the HIV/AIDS epidemic in Botswana. Thou (1996) highlighted a need to empower older women in AIDS prevention and Ingstad, Bruun and Tlouw (1997) examined older persons' perceptions of the disease. Norr, Tlou and McElmurry (1996) explored Botswana women's level of awareness and knowledge of AIDS, while Adeyemi and Tabulawa (1993) described the views of junior-secondary teachers in Botswana on AIDS and related issues. However, no studies have paid particular attention to the effects of the epidemic on the health of older persons, with specific reference to the Community Home-Based Care (CHBC) programme.

The objectives of this review paper are threefold: (1) To examine the experience of older persons in Botswana of the AIDS epidemic, as documented in the literature; (2) to briefly describe the nature of the CHBC programme; and (3) to critically examine the socio-economic and health implications of the programme for the health of older persons, with specific reference to their role as primary caregivers to persons with AIDS and AIDS orphans. It is anticipated that the paper may stimulate debate on the socio-cultural appropriateness of the CHBC model for African countries, while evaluating the extent to which the programme has achieved its objectives and its impact on the quality of life of older carers.

Context

With a population of approximately 1.4 million and a total area of about 582 000 km², Botswana is a sparsely populated country (Ministry of Health, 1997). Although the country has a young age structure (about 29% of the population is below 15 years), 4.8% of the population is aged 65 years and above, one of the highest percentages of older population in sub-Saharan Africa. In 1993, Botswana's real GDP (US\$5 220) was seventh highest among countries with

Address correspondence to
 Dr H.A. Akinsola, Department of Nursing Education, University of Botswana, Private Bag UB702, Gaborone, Botswana.

 E-mail: akinsola@mopipi.ub.bw

medium-human development, ahead of South Africa, Swaziland and Zimbabwe (Siwawa-Ndai, 1997). In 1991, the age dependency rate for Botswana was 94 (15 years and below = 84, 65 years and above = 10); on average therefore, 94 persons (young and old) need to be supported by every 100 persons in the economically-active age group (Campbell & Shastri, 1994). Given the severity of the demographic impact of the AIDS epidemic, a shift in population distribution towards children and older persons, as young-adult mortality increases, may be expected. Inevitably, this trend will increase the already high dependency ratio.

The high rate of HIV/AIDS infection in Botswana and the rapid rate of transmission are documented in several health statistics reports (Ministry of Health, 1991, 1992, 1995, 1996, 1997). According to government statistics (Ministry of Health, 1995), HIV infection has spread rapidly since 1990 in Botswana. Figures from the 1995 Sentinel Surveillance Survey showed that 13% of the total population and 23% of the 15-49-year age group were HIV positive (Ministry of Health, 1997). In 1996, of a total of 4 507 deaths registered in hospitals, 11.9% were due to AIDS, 13.1% to pneumonia and 11.1% to tuberculosis (Ministry of Health, 1997). It is noteworthy that both pneumonia and tuberculosis are AIDS-related diseases, which implies that mortality due to AIDS in 1996 may have been higher than 11.9%. According to Mertens (1995), quoted in Ingstad et al. (1997: 360), "... after lagging behind their neighbours in the north for sometime, the Botswana health authorities are now faced with the situation that their country is one of the hardest hit in the world as far as the prevalence of HIV is concerned." Thus, as a result high rates of morbidity from AIDS and AIDS-related diseases and hospital bed occupancy, the Botswana government established the CHBC programme in the early 1990s. An objective of the programme was to share the burden of care of persons with AIDS with families. The nature of this programme and its implications for the health of older caregivers are discussed later.

Impact of the AIDS epidemic on older persons: case presentations

Three cases are presented in Chart 1, which illustrate the impact of AIDS-related morbidity and mortality on households, particularly households in which older persons reside.

In a discussion paper on the impact of AIDS in Botswana, Campbell and Shastri (1994) emphasised the implications of the epidemic for employment and productivity, two factors which impact the national economy and family health. From an economic viewpoint, Campbell and Shastri (1994: 463) predicted that

the prevalence of HIV among adults is likely to reduce the working life expectancy in Botswana. If deaths due to AIDS affect the active labour force significantly, the need for replacement at that level would reduce the possible effect of unemployment due to redirection of investment initially planned for the economic sector to the health sector. However, due to the low physical resistance level of the AIDS-infected employed persons, there is likelihood that productivity will fall. The possible effect of declining productivity on the country's economic growth is negative. Economic growth will fall and a general state of misery and poverty will prevail.

Kuriah (1992) also projected that the Botswana population growth rate would fall, from 2.7% annually to 1.9% between 1991/1996 and 1996/2001, due to the AIDS epidemic – instead of the projected growth rate of 2.5-2.8% in the absence of AIDS.

Chart 1: Case presentations

Case of Mrs Shabane

Mrs Shabane, aged 75 years, lost eight members of her family to AIDS within the past year and a half. Two grand-daughters are in the terminal stage of the disease. The ages of the deceased (two daughters and six grandchildren) ranged between 18 and 38 years, five were females and three were males. According to Mrs Shabane, all ten cases started with coughing, followed by a loss of appetite and severe wasting, which led to a fatal end within weeks or months. Four of the deceased members were gainfully employed before they fell ill. The two terminally-ill grandchildren receive treatment for tuberculosis in hospital.

Mrs Shabane strongly believes that her family's problem is either due to *moloi* (witcheraft) or a curse. The family at present consists of Mrs Shabane's 94-year-old mother, herself, four orphans of the deceased (aged between two and five years) and the two ill granddaughters. The entire family depends on a monthly pension allowance of P250.00 (approximately US\$56)

Case of Ms Twelo

Ms I welo, 68, lost her only daughter and two grandchildren to AIDS within two years. Her daughter, who was the family breadwinner, died of AIDS-related disease after a short illness. As Ms I welo was trying to cope with the loss of her daughter, her grandchildren (a boy and a girl) died within a year. She has been left as the head of the household and a breadwinner for her great-grandchildren, aged between three and seven years. Her only income is a pension allowance of P110.00 a month (approximately US\$24) and a food ration. Ms Twelo believes that the calamity which her family is experiencing stems from witchcraft.

Case of Ms Mbayi

Ms Mbayi, 58, lost her two daughters, who were single mothers, to AIDS within three years. Her son, and only remaining child, is married and lives in South Africa with his family. He seldom visits his mother in their homestead even when his two sisters were sick. Ms Mbayi is now the head of a household of three, comprising herself and two orphaned grandchildren who are junior-secondary school students. Although the father of one of the grandchildren sometimes gives the family food, Ms I welo's main source of income for the family is the pension allowance.

Sources. Various newspaper items. Individuals' names have been changed and the sources of the items are withheld to protect the identities of the families.

The projections made by economists/demographers less than ten years ago have now become real. As is shown in the case presentations, people are dying in their productive age, leaving behind a highly-dependent population made up of children and grandparents.

Apart from losses to the labour force and productivity, which have dire consequences for the national economy and society, the devastating effect which the epidemic is having on the family cannot be over-emphasised. Poor households are being driven into deeper poverty, as a result of various factors associated with the epidemic, such as a loss of income support as young sexually and economically active indivi-

duals die, high bills incurred while seeking treatment for prolonged HIV opportunistic infections, elaborate funeral rituals (in Botswana funerals last a week on average), and the need to provide for children affected by the epidemic and AIDS orphans (Ministry of Health, 1997).

The major burden of care and provision falls on older persons, as well as on younger women and girl children in the household. In terms of household income, depending on what the situation is in the future, the epidemic may have a cancelling effect on the sustainability of the Old Age Pension Scheme, as the funds may have to be used to support HIV and AIDS related household expenditure (Ministry of Health, 1997). In this case, households will be further impoverished, since the pension benefit is the "life wire" of numerous homes in which young and middle-aged persons are unemployed, are in the terminal stage of AIDS-related illness, or have died of AIDS.

In addition to the economic impact of AIDS, the epidemic has serious social-psychological effects on older persons. In African culture, children are a valued asset to parents, particularly to mothers. They are a main source of social security to elderly parents in the absence of social welfare services for the socially disadvantaged. However, the AIDS epidemic has brought about a reversal of roles: older parents, particularly women, now serve as primary caregivers to terminally-ill adult children and to grandchildren. In addition, they must mourn the deaths of children and grandchildren who succumb to the disease (Mupedziswa, 1997). In the African cultural context, parents pray that they are survived by children and grandchildren, who are expected "to give them a befitting burial." However, the majority of older persons are being robbed of this precious dream by the epidemic. Due to the loss of multiple younger family members, it may reach a point in many African countries where the state will have to take responsibility for arranging burial ceremonies for older persons when they die.

Effects of the CHBC programme on the health of older caregivers

The programme

The Community Home-Based Care programme promotes caregiving to individuals in their natural environment, i.e. their home, by family members supported by skilled social welfare officers and communities, to meet spiritual, material and psychosocial needs, in which care the individual plays a crucial role. The target group for this programme is any person with an HIV-related disease or full-blown AIDS, and chronically-ill persons. A main aim of the programme is to prevent HIV transmission and to reduce the impact of HIV infection and AIDS on the infected and the affected (Ministry of Health, 1997).

A national guideline on the implementation of the programme (Ministry of Health, 1997) sets out the rights of people who constitute the target population in specific terms. For example, the guideline provides a user-friendly format which covers the expected intervention, activity and outcome for the following programme objectives: Provision of quality care services to AIDS patients and their families; mobilization of families and communities to support the programme; a referral system; training; information, education and communication (IEC); counselling; monitoring; and financial issues.

However, questions that are raised are: To what extent are these guidelines being applied in the actual implementation of the programme? What is the experience of the caregivers and the care recipients thusfar?

Effects of the programme on older caregivers and care recipients

Since the inception of the CHBC programme, not much research has been done to assess the quality of the services that are rendered to the target population. However, two studies carried out a few years ago showed that in terms of the programme's objectives and the guidelines for their implementation, not much has been achieved either in sharing the burden of care with family caregivers, in providing physical, financial, social and psychological support, or in preventing the dumping syndrome. For example, a study by Ngwako (1994) on the health, socio-economic, psychological and spiritual support needs of caregivers to persons with AIDS in Botswana showed that the caregivers, who were mainly older women, were lonely, and lacked physical care, financial support, ambulance services and opportunity for communication with health workers. In another study, Molatole (1998) found that most persons with AIDS and their caregivers (mainly older women) did not receive food, medication and transport services under the programme as promised; health care professionals did very little by way of providing material and emotional support to AIDS clients and their caregivers; both caregivers and care recipients expressed a need for financial assistance, particularly to buy food; and caregivers lacked physical support, for example with dressing wounds, and giving bed-baths and medication. Molatole concluded that only minimal social support was available under the programme for persons with AIDS and their primary caregivers. It is noteworthy that both Molatole (1998) and Kebitseope (personal communication, 1998) reported that the programme is largely sustained by non-governmental organisations (NGOs), such as the Holy Cross Hospice which is actively involved in the programme in Gaborone.

Discussion

From an historical perspective, similar to the experience of families in the Community-Based Rehabilitation (CBR) programme for the disabled set up in Botswana in 1979 (Ingstad & Whyte, 1995), the primary caregivers in the current CHBC programme are virtually left to provide for the persons for whom they are caring on their own. This situation is in contrast to the expectation of affected families whose hope for adequate support from government health and social agencies was raised by the government's public awareness campaign through the mass media. Such family members feel that help for persons with AIDS should mean help to them as caregivers, in the form of food, clothes, financial support, transport, emotional support, clinical care, information and education. Thus, they typically feel cheated when such help is not forthcoming. For example, in a daily newspaper, a 70-year-old female primary caregiver was reported to have

I was never given information on how to look after these people. I just gave them food [which] I could lay my hands on because I was not told what they should eat. No one from health service has come to my house to advise me. Maybe it is because I am poor and they feel I do not deserve the right other people have. (Identity and source withheld.)

This remark by a caregiver, made out of deep sorrow and feelings of neglect by health-care agents, represents the sentiments of thousands of caregivers — young and old, male and female, particularly in the rural areas. To many families and health workers, the programme, established among other reasons to avoid the dumping syndrome and unnecessary hospital admissions, and to provide clinical care at home, has failed

to achieve its objectives. As Ingstad (1995: 190) pointed out: if the Community-Based Rehabilitation (CBR) programme should fail, there will be "nothing left but disappointed families and frustrated field-workers."

A group of students recently visited a rural community with the author to gain clinical experience. The community, which is the project site for the WHO Collaborating Centre of the Department of Nursing Education at the University of Botswana, has a population of about 28 000 but no ambulance service. During our tour of the community, a student curiously asked the following question of the nurse in charge of a health post: "You have just informed us about the CHBC programme in the village. Since there is no ambulance service, how do the families transfer their patients to the hospital in case of emergency?" The response of the nurse was that it is the responsibility of the family to arrange transport for the patient. The student then asked the nurse who is expected to pay the transport bill. "The family," replied the nurse.

In the past two decades, when primary health-care programmes were introduced in several African countries, events have shown that primary health care is not cheap either for the government or for people (Chabbot & Waddington, 1987). However, of greater importance is the fact that both providers and consumers of primary health-care services in many African countries, particularly countries experiencing political and economic instability, perceive that government and politicians apply some of the PHC principles (self-reliance, community participation and involvement, sustainability) to shift the responsibility of the government (as the manager of national resources) to ordinary people and non-governmental agencies. The point is that in some countries, the CHBC programme appears to be yet another example of government initiatives in the so-called spirit of primary health care, which is aimed at shifting the burden of care of persons with HIV/AIDS onto the family. As Gubrium and Sankar (1990), quoted in Spradley and Allender (1997: 474), remarked: "Policy makers and health providers have suddenly conceptualised the home as a kind of vacuum into which a wide range of medical services can be transferred; they know little about how health is delivered in households or how families cope." The question begs: In African countries, how can a family which cannot afford to include meat or fish in its daily diet, be expected to provide a balanced diet for a terminally-ill AIDS patient(s)?

At this point it is pertinent to ask why the CHBC programme, in Botswana – or in any African country for that matter, is not able to achieve its objectives in their present form?

Any complex problem, such as the one being discussed, calls for a complex solution. It is unlikely therefore that a single theory may explain the dynamics of the problems being faced by the CHBC programme. However, as in the case of the Community-Based Rehabilitation (CBR) programme adopted in Botswana some years ago but which subsequently failed (Ingstad & Whyte, 1995), the CHBC model was also adopted by politicians and policy makers in Africa without critical examination of its appropriateness in the socio-cultural context. Perhaps the model can work in developed countries where an ideology of equal rights and state responsibilities for the underprivileged is strongly entrenched in the countries' constitutions, and the law is strictly adhered to under the eyes of advocates of equal rights and politicians who have genuine interest in the constituencies which they represent. In developing countries of Africa, there is no strong concept of the equal individual. Instead, African societies have always been hierarchical, with some people ranked higher than others, either by virtue of health status (the sick versus the healthy), age, gender, wealth, political power, education or ascribed traditional status, such as membership of a royal family. As recently observed by Shaibu (personal communication, 1999), the image of self in the African context is pluralistic (always "we"), in the sense that each believes that he/she belongs to his/her family and that the survival of that individual is dependent on the collective efforts of the family and not individual effort, notwithstanding social status, i.e. being rich or poor, educated or illiterate, healthy or sick. In other words, the state is never perceived by either an individual or a community as a source of social security. Based on this premise, the responsibility for the provision of care for socially deprived people, such as older persons, the handicapped and the sick, is traditionally seen as the sole responsibility of the family, particularly women and girl children.

The theoretical framework presented above is supported by the findings of several studies in Africa, which examined the way in which households in different settings render care in contemporary circumstances. In Tanzania, Susan Whyte (1991) found that people with mental illness, retardation and epilepsy were always cared for by family, and care was regarded as a family and not a community responsibility. Previously, when families were large, the burden of care could be shared. However, labour migration and poverty have transformed family situations in Tanzania. In Zimbabwean (Saugestad, 1990) and Botswana (Ingstad et al., 1992) villages, it is often grandmothers who care for disabled children because parents - often unmarried mothers - are away at work in towns. In these rural communities, labour migration removes healthy and able members from households and leaves behind old, very young, disabled and sick members who must survive on subsistence farming and irregular remittances. Previously, caregiving within households depended on family resources (Walman, 1984), family members' willingness to give care priority over other needs and goals (Ingstad et al., 1992), and the active support of the extended family, particularly children who were expected to show their parents respect and to give them support. In contemporary African countries, factors such as urbanization, unemployment, poverty, a low marriage rate among adults in the communities and the AIDS epidemics have disrupted the social organization of the family.

However, despite transformation of the African family, societal orientation has not changed. The element in the definition of the CHBC programme, which states that the individual will be "supported by skilled social welfare officers and communities to meet spiritual, material and psychosocial needs," is therefore no more than political rhetoric. In other words, since there has been no paradigm shift in the orientation of the majority of African political leaders towards the basic issue of equal rights and state responsibility for the underprivileged, the needs of this category of people and their caregivers will not be given priority attention. The introduction of the CHBC programme has thus been no more than an attempt to reinforce a cultural belief that the family must care for the sick. No consideration has been given to the seriousness of the effects of the AIDS epidemic, as reflected in the case presentations above.

Conclusions and recommendations

Caregiving to persons with AIDS under the CHBC programme is thus a complex matter, which imposes physical, social-psychological and financial burdens on the families, many of whose members are older persons. Family members probably cope with the burden of care, because

social norms in Africa do not permit an individual to reject kin who are experiencing a serious problem, particularly a serious illness. An individual who rejects kin in such a situation is labelled as a witch and may be suspected of being responsible for the relative's predicament. From a gender perspective, it is even more risky for older women to be observed to show a lack of tolerance for a relative who is seriously ill; in many traditional African communities, older women are frequently unfairly suspected of practising witchcraft.

The situation reviewed in this paper calls for strong policy action in addition to the implementation of existing policy. Various levels of government must be informed of the situation in households. The 21st-century family is quite different from the family of some decades ago, when technology was relatively undeveloped and communities had resources to provide for families' needs. Today, governments control the vast majority of resources and they must discharge their responsibilities to ordinary people who form the electorate.

For the CHBC model to work in this continent during this period of economic recess and rapid social transition, the programme must be transformed into one that is more culturally attuned, taking into consideration current poverty levels of households, levels of morbidity and mortality experienced by families due to AIDS-related illnesses, and disintegration of the extended family system as a result of migration and the adoption of urban life-styles. For example, the demands and challenges of caring for persons with AIDS at home need to be critically weighed against available meagre resources in homes, particularly in the rural areas where poverty is greater. The involvement of older persons, particularly women, as primary caregivers to persons with AIDS is an issue that warrants urgent attention. People in that age group may suffer poor health as a result of chronic diseases of old age, particularly arthritis, diabetes, hypertension and heart disease. The government should therefore first assess the ability of families to care for persons with AIDS at home. An assessment should include demographic factors, such as family size and composition, as well as the organization of the household economy and social activities. Based on a determination of a family's capacity and needs, health workers may be deployed to pay regular home visits and to provide care in homes where the need is greatest.

Considering the gravity of health and socio-economic problems created by the AIDS epidemics within communities, countries which are seriously hit by epidemics should set up a high-powered National Commission on AIDS. A commission should serve at least three purposes: (1) To develop culturally and economically sound strategies to break the cycle of transmission of the virus; (2) to promote research on different aspects of the disease, including the development of an appropriate vaccine and drugs; and (3) to plan and monitor the treatment of persons with HIV/AIDS by laying specific emphasis on hospital admission policy, patterns of treatment and care of in-patients, discharge planning and the quality of CBHC services.

The majority of hospitals in Africa are overburdened with cases of AIDS and related diseases and the quality of care received by patients is suboptimal. In some hospitals, AIDS patients are simply dumped on beds or the floor of wards, to await death. In the past several countries built special hospital facilities to cater for epidemics of specific diseases, such as smallpox, tuberculosis and cholera, and consideration should now be given to the development of special hospitals for the care of AIDS patients. Specific attention needs to be focussed on the needs of these persons and their families, whether they are in hospital or at home.

The author is not challenging the principles upon which the CBHC programme is based; rather, a need is advocated to evaluate the programme, to identify its merits and demerits with an aim to improve its implementation. In this way, both the quality and quantity of services rendered to persons with AIDS and their families in Africa, as well as their quality of life may be improved. The World Health Organisation and African countries have declared the AIDS epidemics a disaster situation; they should therefore be treated like any other disaster, such as a war or an earthquake.

Finally, even though the official International Year of Older Persons 1999 has ended, the serious challenges which the Declaration poses to the global community remain fresh. On the part of the youth and middle-aged parents, one of the greatest challenges is a need for individuals to resolve to adopt a healthy sexual life-style and in so doing, to break the cycle of the AIDS epidemic in communities and thus its impact on families, particularly older members.

Note

Botswana has a universal pension system, whereby all Botswana nationals aged 60 years and over are eligible for a pension allowance of P110.00 (approximately US\$24) a month.

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IN MEMORIAM

Donald Adamchak

It is with great sadness that we inform readers of the death of Donald J. Adamchak in Manhattan, Kansas, USA on 16 March 2000. Adam, as he was known to all, was a Professor in Sociology at Kansas State University. He served on the Editorial Advisory Panel of *SAJG* since the Journal was launched in 1992. He loved Africa, and has contributed significantly to the expansion of African gerontology through his sojourns and research projects in several African countries, his notable publications output, and his devotion to the training of students in demography and gerontology. His editorial guidance to *SAJG* over the years has been enormous and valued. We extend our sincere condolences to his loving wife and our dear friend, Susan.