The plight of family caregivers in home based care in Botswana

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Abstract

The opportunity cost of those caring for HIV/AIDS clients is enormous. The probability of family caregivers contracting the virus due to exposure is high. Consequently, the caregiving environment is fraught with fear of infection. In Botswana Home Based Care (HBC) is seen as both a strategy and a solution of dealing with problems such as a lack of capacity in the health care delivery system and inadequate resources for HIV/AIDS care and management. Conversely, the burden of care and the human suffering experienced by HIV/AIDS patients and their families cannot be over-emphasised. The purposes of this paper are to: (1) assess human suffering experienced by both HIV/AIDS persons and their caregivers; (2) examine some of the challenges facing caregivers in HIV/AIDS care and management in a home care setting; (3) discuss the progress and implementation of home based care in Botswana.

Introduction and background

Historically, the sick have been cared for in the context of the family, and children in adult life have taken care of their elderly parents. Care giving in the home was mostly limited to the elderly, children and disabled persons, and the numbers of those cared for were low. With the advent of the human immune deficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) there is a role reversal in caring. Parents find themselves in a very difficult situation caring for their dying children, or breadwinners. In Botswana home based care programmes are characterised by severely sick people, and the numbers in home care continue to rise substantially due to HIV/AIDS. HIV/AIDS demands more difficult care over much longer periods of time than used to be needed only a generation ago.

The literature indicates that care giving involves a commitment of time and effort that may be made at a high price to the self. Nodding (1984) posits that for care giving to be complete, it has to be recognised by the cared-for person, which is at times hard to establish. Another potential risk associated with caring for HIV/AIDS clients is the increased probability of contracting the virus due to exposure. For instance, if the caregiver has become too committed to caring for the other, they cannot be preoccupied with self, thus compliance with universal precautions to prevent cross-infection could be neglected, and as a result the caregivers' own health needs may be compromised.

Similarly, Jaggar & Bordo (1992) point out that the essential aspect of caring is that it involves a displacement from one's own interests to the interests of the one cared for. Caring affects the one caring because she must become engrossed in the other. It also affects the cared-for because that individual's needs are met by others, and because that individual must somehow respond and accept the care offered. They further argue that caring cannot simply be a romanticised notion of selflessness, nor can it occur if the self remains aloof. Family care giving as a social phenomenon implies that there is a social and political dimension to it. To gain some understanding in home based care a review of the concept is critical.

The concept of community home based care (CHBC) was introduced in 1992 when it became clear that public hospitals were not coping with the increasing number of AIDS patients. The development of the CHBC system began two years later. The first two pilot projects started in Tutume and Molepolole. Until then family members had to care for relatives living with HIV and

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AIDS without the support or counselling an active CHBC could offer (WHO 2000).

Community Home Based Care (CHBC) is the care given to individuals in their own natural environment, which is their home, by their families, supported by skilled social welfare officers and communities to meet spiritual, material and psycho-social needs, with the individual playing a crucial role. The target group for this programme is any person with HIV-related diseases including all other chronically ill patients (NACP 30 1996 p3).

In Botswana the family was traditionally considered and still is the caring unit in society, therefore a programme that builds on it was most likely to be successful and effective (NACP 31, 1996). Home based care, as a strategy to alleviate the increasing pressure from the frail health care system, is problematic for caregivers. Most caregivers assume care without the necessary knowledge and skills nor the material resources necessary for HIV/AIDS prevention and management. This presents problems for health care providers, specifically nurses in Primary Health Care (PHC) settings with regards to the supervision, monitoring and follow-up of clients.

From a policy perspective resources are limited, and there is need to conserve them. However, recognition of the need for inexpensive long-term care alternatives should not shift the burden of care from the health care delivery system to the people. While active involvement of family members in CHBC is encouraged, caution should be exercised. For families to be actively involved in CHBC, there is need to recognise that the knowledge requires constant changes.

Consequently, Dwyer and Coward (1992) argue that families are viewed not simply as stakeholders but as a cost containment resource capable of the care they can do now. They further argue that this evolution in the emphasis placed on family care giving has fuelled ongoing debate between those who urge the development of public policies supportive of family care and those who wish to place even greater responsibilities on the family as a means to deal with the rising costs of health care.

The literature on CHBC suggests that patients prefer to be to be cared for by their loved ones and/or die peacefully in familiar environment. However, what the literature does not tell us is whether family members have any choice to decide to care for their HIV/AIDS infected relatives or not. Home based care, as currently conceptualised and practised in Botswana, dictates that the responsibility for the care giving of HIV/AIDS clients and other chronic illnesses must be assumed by their families.

The rapid increase in the incidence of HIV/AIDS has implications for both family care giving and the national health care delivery system. The issues of quality care and cost effectiveness pose major challenges for home based care. The human suffering experienced by both the patients and their families due to increased morbidity and mortality in CHBC cannot be over emphasised. Given the complexities of family care giving in home care, the purposes of this paper are to:

1. Assess the human suffering experienced by both HIV/AIDS persons and their caregivers;
2. Examine some of the challenges facing caregivers in HIV/AIDS care and management in a home care setting;
3. Discuss the progress and implementation of home-based care in Botswana.

The challenges facing caregivers

The burden of HIV/AIDS in Botswana is the highest in Sub-Saharan Africa, where 83% of the world AIDS cases have occurred, and where 80% of all HIV positive people live. The epidemic began to spread in Botswana in the 1980s, and in the 1990s HIV prevalence increased dramatically (UNDP 2002; UNDP 2001; NACA Technical Report 2001). The UNDP (2002) Human Development Report for Botswana indicates that more than a third of adults have HIV/AIDS and that a child born today can expect to live only 36 years—about half as long as if the disease did not exist.
Research on home based care for people living with AIDS indicates that most people cared for at home do not necessarily wish for it, but accept it because the scale of the HIV/AIDS epidemic and the inadequacy of health budgets in developing countries require it. By 2010 over 30,000 AIDS deaths per annum are projected. HIV/AIDS will profoundly affect the age profile of the Botswana population over time. At present some impact of HIV/AIDS is expected to be apparent mainly in the youngest age groups. This trend is due to HIV-related reductions in women’s fertility and the short incubation period for children infected at birth (UNDP/MFDP 2000).

The plight of caregivers emanates from the social, cultural and political dimensions of caring as defined by society. The definition of caregiving draws from the 'ethic of care' which is characterised by a commitment to maintaining and fostering the relationship into which one is woven. It asserts that families have responsibilities and obligations to other family members. While this is true, home based care should be discussed in the light of the social transformations and changes that Botswana society has been undergoing, including the risks, conflicts and costs involved. The extended family that Batswana traditionally depended upon for support in long-term illness is slowly fading away. It is not always available and capable of sharing responsibilities of care as initially perceived when CHBC was conceived.

Jackson and Anderson (2001) posit that the burden of coping with the patient falls increasingly on family members who not only lack knowledge and information but in most cases do not even know the patient’s diagnosis, although they may suspect AIDS. In addition, the burden of care and death multiplies within the family if, for example, both husband and wife die or young children fall sick.

What is at issue is the ability to set the parameters of care, such as decisions about providing care and when to stop providing care. From the literature it is evident that care giving varies with the amount of time and kind of effort that a caring individual can expend as well as with the needs of the ones who need care. WHO/MOH (2000) reports that family caregivers in most cases are caring for more than one patient. Care giving activities include both personal care (bathing, feeding, dressing, mobilisation, etc) and instrumental activities of daily living such as collecting water and wood, cleaning, obtaining health supplies and shopping. Caregivers also report feeling depressed, lonely, isolated and overwhelmed with all the responsibilities that had been thrust upon them.

The selflessness implied in family care giving at times precludes caregivers from acknowledging caring for others as a burden due to fear of being labelled selfish and uncaring. The risks involved in HIV/AIDS care and management need to be fully addressed if home based care is to become effective. In order to engage in the practice of caring the nature of knowledge and skills need to be determined up front. Caregivers need knowledge about the disease, resources, risks, costs as well as the needs of their clients.

The literature on HIV/AIDS care indicates that caregivers are usually mothers, grandmothers, sisters and in some cases girl children. In Botswana those caring for HIV/AIDS patients are mostly older persons whose immune system and health are already compromised, thus making care giving a difficult task. The fact that most caregivers are elderly persons has implications for the quality of care in CHBC. The AIDS/STD Unit (1996) reports that there was consensus among medical personnel and welfare officers that, compared to the care given at hospitals, the quality of home based care as currently practised is below standard except from the point of view of emotional support.

Financial and psychological costs

It appears as if there is a social disregard for the costs of care giving. Society considers the unpaid labour of family caregivers as ‘low cost’ to individuals, to families and to communities because not all the costs of labour are assessed. Caregivers sacrifice their financial independence to meet their social obligations to be unpaid caregivers. Such costs are borne disproportionately by women. In addition to financial costs, there are psychological costs as well. Given this premise, it seems reasonable to assume that health care costs have been diverted from government to family caregivers,
primarily women. While women experience significant and extensive costs through their caring labour there is a social disregard for those costs.

Jackson and Anderson (2001) argue that AIDS is a major factor in the impoverishment of families as they lose productive, household and subsistence labour. Expenditures rise for health care, transportation to hospital and clinics and funerals. Many families resort to spending savings, selling productive assets and removing children, especially girls, from school and reducing their long-term security to finance the present crisis. Consequently, home based care imposes considerable costs on patients and their family caregivers in terms of time, financial resources and opportunity costs. For instance, patients may have special nutritional requirements that require extra money and time spent on food acquisition, preparation and feeding—money and time that are often not available for other family members’ food requirements or other needs.

In Botswana the actual costs of home care are not known because the home-based care programme has not been evaluated. To date there is no data on its cost effectiveness and cost benefit. In Zimbabwe, Jackson and Anderson (2001) report that in 1994 four home based care programmes were studied and the estimated cost by households in caring for a bedridden patient was between US$68 and US$103. This demonstrates that home based care is not necessarily a cheap alternative for the households and communities involved. Nevertheless, it has been noted that the costs of CHBC that involve large numbers of volunteers need not be much higher than for programmes working with a few volunteers, and the scale of service provision and potential for sustainability are notably higher.

Poverty

The HIV/AIDS epidemic has introduced a new long-term trend in impoverishment. One of the principal effects of AIDS at the individual level is that the household of the victim will become poorer. In South Africa this is attributed to high expenditure on travel, admission fees, fees for healers, clinic fees and funeral expenses, as well as loss of labour from the sufferer and caregivers (Narayan et al. 2000). In Botswana poverty also poses serious problems for community home based care. With 47% of the population reported to have been living in poverty in 1993/94, home based care faces ethical problems. The poor sanitary conditions in both urban and rural areas pose real danger to both the patient and caregivers. With their immunity already compromised people living with AIDS face heightened risks of infection in such areas (Botswana Human Development Report 2000).

Poverty is pain. Poor people suffer physical pain that comes from little food and long hours of work, emotional pain stemming from the daily humiliations of dependency and lack of power. In addition there is the moral pain of being forced to make choices—such as whether to use limited funds to save the life of an ill family member or to use those same funds to feed their children (Narayan 2000).

The Botswana social welfare system is residual. Therefore access to services is not always easy (MLG & H 2000). There is a general lack of knowledge among caregivers of accessing this vital information. Anecdotal evidence suggests that the home based kit that was designed to provide families with supplies is in most cases not available in the local health clinics. The destitute programme, which should assist poor people with food rations and other materials such as blankets, mattresses and school uniforms, has also been difficult to access.

First of all, the social workers are not equally distributed among the districts and villages. In most rural villages there are no social workers to carry out family assessments to determine their needs and/or assist the families with completion of forms. Secondly, the application process for destitute funds is too long and tedious. Some caregivers were reported to be too embarrassed to ask for assistance to the extent of preventing older caregivers applying for the destitute allowance even though it was desperately needed.

1 MLG & H refers to Ministry of Local Government and Housing.
Risk of infection

Care giving in home based care entails risks. The lack of adequate knowledge of HIV/AIDS prevention and management is a serious problem. There is very little training, if any, for caregivers and yet they are expected by the health team to provide care with some level of proficiency. Given the multiple roles and problems caregivers are faced with, how are they expected to function? Phaladze (1999) reported that the risks of perceived cross-infection in CHBC was great, as illustrated by the following comments and questions:

What support systems do we have in communities to assist caregivers and people living with HIV? Do caregivers know how to handle ‘infectious persons’? Do they have the knowledge and skills? How do we foster compliance with universal precautions in a society where care giving involves multiple caregivers? To sum this up one respondent had this to say: ‘I always shiver when I think of a situation where an entire family could be wiped out Go bo go tswalwa ka lethaku due to cross-infection in CHBC because the family has not been fully prepared to handle AIDS clients’ (p111).

Staff turnover

The current changes in the health care environment also threaten the survival of CHBC programme. At present Botswana is experiencing serious manpower constraints, specifically nurses, who are the corner stone of the health care delivery system. Nurses are leaving the country to work abroad, and this has implications for the effective implementation of the CHBC. The professional support of supervision and monitoring is desperately needed in CHBC. Without that the programme faces serious problems.

The CHBC programme has been experiencing problems without the nurse exodus, but with the new developments its existence may be short-lived. The problems plaguing the health care delivery system have serious implications for the provision of health care services. There is need to review the programme in the light of new information and current changes if the CHBC is to be sustained. It is no longer enough or relevant to say that home based care will increase the access of AIDS-affected families to skilled health care when there is inadequate staff and when caregivers are overstretched. Similarly, support and assistance from members of the extended family cannot be guaranteed as well, due to the economic pressures most families are experiencing. The sheer burden of care giving does not allow caregivers opportunities to engage in income-generating activities that are critical for their own survival and livelihood.

Although some studies have shown that most patients with AIDS and other chronic illnesses prefer to die at home as opposed to in the health facility, the lack of resources to provide quality of care in home based care might reverse this preference.

The literature indicates that some caregivers have had to provide care for relatives living with AIDS without the support and counselling an active CHBC could offer (WHO 2000; Botswana Human Development Report 2000).

The burden of care giving is immense, and many caregivers are themselves ill. Although no figures were provided for caregiver mortality, it is reported that caregivers themselves die after caring for family members (WHO 2000). While the impact of HIV/AIDS on the health sector is great, the discussion of CHBC should take cognisance of the arduous tasks caregivers have to undertake. The knowledge gained from these discussions will generate data that can inform public policy on appropriate strategies and/or interventions.

Stigma

Another major challenge faced by caregivers and their clients is stigma. The stigma associated
with a diagnosis of HIV/AIDS naturally limits programme effectiveness. Programmes for counselling and treatment need to address the fear of social isolation, which leads many households and individuals to hide the fact of infection.

WHO/MOH (2000) also reports that the experience of stigma goes beyond issues of HIV/AIDS, and is also experienced by people and families living with other chronic illnesses. CHBC and non-governmental organisations (NGOs) that organise and provide care for people at home have been stigmatised with the label of HIV/AIDS care. Findings from caregivers, studies of ‘stigmatised’ conditions show a consistent pattern reflecting lack of support (Noberck et al 1991, Cossette, Levesque and Laurin 1995; Robinson and Austin 1998).

The literature and anecdotal evidence in Botswana also reveal that stigma prevents people living with HIV (PLWHs) from accessing health care services. Some families have been reported to have refused care because they did not want their neighbours to see an NGO or CHBC team member enter their homes for fear of social isolation. This therefore calls for an urgent review of the CHBC programme with regard to quality of patient care as well as quality of life for the patients and their families.

Social support

The literature on social support for family caregivers suggests that caregivers experience a lot of difficulties while caring for their loved ones which include: acceptance of the patient’s diagnosis, commitment by others to the patient, informational needs related to the illness and management for helping accessing resources, need for respite care and direct help with care giving activities (Noberck et al 1991; Shaibu 1997).

Fear and the omnipresence of death

Another challenge faced by caregivers (especially parents) is fear about the future, that is, what would happen to the terminally ill person should they themselves die before the patient. There is also fear of the inevitable death of those suffering from AIDS, and this is one of the major sources of human suffering and pain experienced by both caregivers and their clients since there is no cure for AIDS. This fear eventually might lead to depression as referred to in the literature. Depression may further negatively impact on care giving by reducing the energy necessary to build and maintain supportive relationships.

Similarly Robinson and Austin (1995) posit that depressed caregivers might perceive care giving problems to be more severe and resources might seem less available to them than they really are. Furthermore, if the caregiver experiences an actual or perceived lack of support this may in turn intensify the impact of negative feelings.

Conflict

In Botswana care giving decisions usually involve several family members, including the extended family, and this may increase the probability of conflicts. Study of the involvement of the extended family in care giving should look at all the critical dimensions of caring. The extended family can be a resource as well as a problem or constraint for those involved with direct patient care. Given the challenges caregivers face in home care, it seems appropriate to examine the progress and implementation of CHBC.

Progress and implementation of home based care

The national home based care sub-unit has been established in the AIDS/STD unit in response to the increased demands of clients with terminal illnesses. The home based care unit was allocated
twenty-seven million pula (P27 million) to facilitate the unit’s activities in providing leadership on this aspect. The money was intended to cover personnel, material supplies, training and transport for health care providers at the community level. It is also reported that the home based care unit was highly publicised through the media (personal communication, Coordinator, National Home Based Care 2000).

To date there has been lot of awareness created on the HIV/AIDS issue in the country. Political commitment to the epidemic is reflected by several public speeches made by politicians, including the Head of State and public documents generated such as MTP I, MTP II, NDP 8 and the Botswana Human Development Report 2000. Despite the establishment of the HBC sub-unit and information generated on CHBC, problems still remain. For instance, health workers with very limited diagnostic and treatment skills staff most Primary Health Care (PHC) clinics, health posts and mobile clinics. They also have limited HIV/AIDS specific knowledge to enable them to effectively deal with HIV related conditions. In addition, the referral system from hospital to PHC centres tends to be very poor (MFDP/UNDP 2000).

While several strides have been made in CHBC, such as the development of an HIV/AIDS guide for caregivers and health professionals, a lot more needs to be done to ensure effective implementation of the CHBC policy. The language used to develop the caregivers’ guide is English, which may render it less user friendly because most caregivers in CHBC cannot read or write English. A directory of the CHBC service was also developed in response to the increasing demand of CHBC services available. However, the question that remains to be answered is whether these documents have been publicised, and if they are available and accessible to a wider community.

The literature on home based care elsewhere, and in Botswana in particular, has consistently reported a lack of information given to caregivers. The overall implementation for HBC in Botswana has been slow and has lagged behind the rapidly increasing need (Phaladze 1999; MFDP/UNDP 2000). For adequate implementation to occur there is need for a well-crafted implementation plan if the mission of CHBC to facilitate the provision and expansion of quality care for the needy is to be realised.

Home based care, which is perceived as an essential component of the Botswana health delivery system, needs to be reviewed in the light of current data. The problems plaguing CHBC, such as the lack of capacity in many households to provide care, poverty, stigma, lack of information and a poor referral system, need urgent attention. Community home based care as a strategy for providing continued care in the home also presents ethical challenges for nursing such as the supervision and monitoring of these clients, non-maleficence (avoiding harm), beneficence (doing good) and distributive justice where demand exceeds supply. Who is ultimately responsible for the patient’s care? Explicit consideration of these ethical challenges would assist nurses, family caregivers and clients in decision making. Hence there is a need to determine what the role of nursing is in community home based care in Botswana.

The role of nursing in community home based care

The profession of nursing has an obligation to face up to the challenges presented by HIV/AIDS in its role of patient advocacy. Amid a myriad of problems presented by the epidemic, nursing has the challenge to retain its existing staff and recruit new members into the profession. However, what is currently not known is whether the challenges and demands imposed by HIV/AIDS care and the attrition rate of nurses will deter or encourage existing staff to stay and encourage new applicants to join.

To ensure that CHBC becomes effective, nursing has to become politically active in public policy issues pertinent to the practice of nursing. Nursing also has to recognize that the most important reason it exists is the patient and his/her family. As the largest group of health personnel, nurses can make a difference in alleviating the human suffering experienced by our clients and their families.
Mortality

The fact that all patients suffering from AIDS will eventually die is a fear caregivers face on a daily basis. Most of these patients are young adults who might never have had to face illness, hospitalisation or issues of death and dying. Both nurses and families have in most cases dealt with dying in the context of the aging process, and as such we are less prepared to handle the death of young people and its consequence—orphans. Nurses can assist families in CHBC to identify and deal with their feelings about death and dying. Although many of us believe that death is part of life, and have religious and philosophical perspectives that allow us to manage our feelings, most of us still have difficulties dealing with the losses we are currently experiencing as a result of AIDS.

Fear of infection and conflict

Although the Ministry of Health and its departments have launched massive education on HIV/AIDS facts, the information gained might lose meaning when fear sets in, and this may result in conflict. When caregivers are confronted with the possibility of their own death due to an ‘occupational’ risk as a caregiver, the quality of care provided to clients may be compromised—regardless of commitment, compassion or the affection the caregiver has for the patient. Nurses should be in a better position to deal with their own fears as well as those of caregivers’ through continued education on universal precautions, and ensuring adequate resources for HIV/AIDS prevention and management.

Pain and suffering

The cumulative losses that caregivers experience when caring for their patients with AIDS is immeasurable. As their patients suffer, they too suffer. This suffering is usually characterised by feelings of helplessness and despair. As nurses we have been trained to reduce suffering and offer consolation to those who are suffering. Adinolfi (1996) cautions that our resources are very limited in what we can offer to patients with AIDS and their families, but our best method of preservation is to know our limitations and to be able to do our best at all times.

Conclusion

Previous studies on home based care present conflicting ideas on whether CHBC is a better solution, given the archaic conditions under which most of the caregiving takes place in Botswana. The arduous tasks facing caregivers in the home setting also present major challenges pertaining to quality care issues. While political commitment is appreciated, the hardships experienced by caregivers in my opinion outweigh the benefits.

For instance, most communities lack a full range of habilitative and rehabilitative services. The human suffering caused by the lack of knowledge of what kinds of resources are available to people, coupled with health providers’ own limited knowledge, demands immediate attention. It is also worsened by the increased workload in acute care settings preventing nurses from doing follow-ups.

Finally, the initiation of CHBC should not exonerate the government from its social responsibility and obligations, especially the Ministry of Health. A comprehensive social policy is long overdue! (Phaladze 1999).
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2 MFDP refers to the Ministry of Finance and Development Planning
3 NACA refers to National AIDS Coordinating Agency
4 MOH refers to the Ministry of Health