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HIV/AIDS and Home Based Care in Botswana: Panacea or Perfidy?

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SUMMARY. The extent of the AIDS pandemic in Africa (and specifically in Botswana), and the lack of institutional frameworks to address concomitant issues, have necessitated the adoption of home based care for sufferers as national policy. The practice is beset by problems, given the severe symptomatic nature of the disease and the general lack of human and material resources to address the needs of patients and care-givers.

A study of one such programme in the Kweneng District of Botswana highlighted gender imbalances, poverty, lack of appropriate skills, over-involvement of the elderly, deficient specialised facilities, need for volunteer capacity building, inadequate income generating activities, insufficient counseling services, and culturally determined cognitive processes as areas requiring urgent attention. It is apparent that the programme needs strengthening through appropriate support mechanisms and that alternative strategies should be devised for those whose circumstances demand them.

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The international hospice movement, represented in Botswana, exemplifies a philosophical and service model for multisectoral consideration and implementation on a nationwide scale. The article discusses, inter alia, day care centres and residential units for the terminally ill; a system of highly trained volunteers to work with patients and their families; consistent, skilled nursing services in home based care situations; and halfway houses for training of care-givers as possible solutions to the problem.

The contextualization of such measures will undoubtedly assist in bolstering Botswana's unchallenged record of high standards in governance and social development. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2004 by The Haworth Press, Inc. All rights reserved.]*

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INTRODUCTION

Home based care (HBC) can be conceptualised and implemented in many different ways; however, as a theoretical concept it should always aim at providing quality care for terminally ill patients and *not* be seen as a solution to overcrowded hospitals. The authors of this article are of the opinion that home based care has the potential to provide patients with the best possible care at home, but that there are limitations which need to be squarely addressed in order to make a national HBC programme a success. Caring for sick people in society and integrating the community in such an activity is not a new concept in Africa, but with the arrival of the AIDS epidemic, the dimensions to care have changed to a degree that government, private sector, and civil society initiatives are urgently needed.

Since the early 1970s, Botswana has based its health policy on the concept of universal health care with an understanding by the Government that access to health care is a basic human right (Government of Botswana & UNDP 1998). The underlying mission has been to provide health care for all, and the country's performance in this regard was exemplary until the HIV epidemic reversed many of the achievements in the health sector. The countries of sub-Saharan Africa generally have the lowest ratio of hospital beds to population in the world, eight to ten times lower than the European average, and

scarcer still in rural areas. Special care and longer time frames associated with HIV/AIDS treatment further increase demand for already limited resources (Hope 1999) and, given the scale of the epidemic, Botswana is now a part of this critical situation.

The following argument is based on the assumption that terminally ill patients, in a country like Botswana, should have the right to choose their care environment and that they are entitled to the best possible care available. Currently, patients in Botswana are denied this choice because health workers are obligated to transfer any terminally ill patient to their home if the patient's physical condition allows them to do so, a criterion subject to discursive interpretation. The first part of the paper indicates some of the shortcomings of the current home based care system in Botswana, while the second part discusses alternative and supplementary services that would, it is believed, improve the care given to clients. The authors consider that the current implementation of home based care in Botswana is an unethical solution to the care crisis and argue that appropriate adaptation of the hospice philosophy would improve the situation for all those affected by the epidemic. The role of social workers in this context is examined and suggestions made for their greater involvement in the continuum of care.

THE CONCEPT OF HOME BASED CARE IN BOTSWANA

Conceptually, home based care is a form of community care. In the United Kingdom, for example, community care was officially established as policy in 1990 (the NHS and Community Care Act) to address the needs of the elderly, people suffering from chronic illness, and those living with disabilities (Braye & Preston-Shoot 1996). The key objectives of this model of community care are to promote the development of domiciliary, day care, and respite services to enable people to live in their own homes wherever possible; to ensure that care-givers receive maximum support; and to develop a flourishing independent sector beside quality public programmes through state purchase of services provided by non-governmental organisations (Department of Health 1989).

Domiciliary and day care centre services are available, to a limited extent, in Botswana in the form of home nursing programmes provided by local authorities and non-governmental organisations and a small number of day care centres for the terminally ill. The latter also constitute essential respite services for care-givers. However, a great deal more needs to be done to make home based care a viable alternative to hospital care, especially for HIV/AIDS

sufferers and their families. Even in Britain the community care concept has proven to be riddled with complications, exemplified by the observation that

To the politician community care is a useful piece of rhetoric; to the sociologist it is a stick (with which) to beat institutional care . . .; to the civil servant it is a cheap alternative to institutional care which can be passed to the local authorities for action or inaction; to the visionary it is a dream of a new society in which people really do care; to social service departments it is a nightmare of heightened public expectations and inadequate resources to meet them. (Jones et al., 1978: 114)

However, community home based care is characterised by a number of aspects that make it a suitable solution in response to the HIV epidemic in a developing country. Since resources are increasingly limited in the public health sector due to the growing number of people falling ill with AIDS related diseases, the state is forced to look for alternative ways to care for these clients. In Botswana, according to the 2000 sentinel surveillance, 38.5% of the population between 15 and 49 years are estimated to be infected with HIV (NACA, AIDS/STD Unit, WHO 2000). Several hospitals currently record that up to 80% of patients in some wards and up to 30% of patients in paediatric wards are hospitalised due to HIV related conditions, while during the period between 1990 and 1996, hospital admissions doubled on a national level (Government of Botswana & UNDP 2000). The increasing pressures on the health system have forced health authorities to relocate patients suffering from AIDS related diseases back into the community in order to be able to provide adequate care to patients with curable diseases.

The concept of home based care lies at the heart of Botswana's national response to the epidemic. At the end of June 2000 the cumulative figure for clients registered on home based care stood at 7,000, with the great majority of clients on the programme suffering from AIDS related diseases. Additionally, there is a growing number of children living with an ailing parent or parents and in the year 2000 the number of reported cases was 6,823 (AIDS/STD Unit 2000: 12).

In addition to releasing pressure from hospital facilities, community home based care also has the positive potential to unite aspects of care with prevention, which in the past have been commonly treated as two exclusive concepts. By including the family and the community in the care of AIDS patients it becomes possible to discuss prevention within the community. Once AIDS patients are considered a reality it is easier for people to accept their responsibility to prevent further transmission of the virus (AIDS Action 1995: 2). A view shared by the Government of Botswana:

Caring for patients with AIDS is probably the best way for families and communities to perceive AIDS as a reality in the community and for their own lives. A caring family will also be the best guarantee for prevention of ostracism of people living with HIV/AIDS. (AIDS/STD Unit, Ministry of Health 1996: 4)

Through care in the community, it is thought that the discrimination and isolation of HIV positive people and their families is prevented. However, care within the community should not divert responsibility from the health authority, and there needs to be an understanding that even the institution of the extended family within the African context has its limitations in terms of its ability to care for terminally ill family members (McDonnell et al., 1994: 429).

Also, the ability of the community and the family to provide care needs to be assessed within the economic context of the country and in relation to existing gender imbalances. In regard to the latter, the authors have argued elsewhere that the great majority of carers in Botswana are elderly, and often poor, women while at the same time more women than men are infected with the virus. One could, therefore, argue that the burden of care is placed on the women of Botswana who often live in extremely poor economic conditions (Stegling 2000). Women are generally more affected by poverty than men, making them not only more prone to adopt survival strategies, which might include 'risky' sexual behaviour (Bainame & Letamo 1997: 99) but also making it more difficult for them to look after AIDS patients. Culture also plays a role in the vulnerability of women with regard to risk taking in patient care. This is observed in the unwillingness of many care-givers to wear protective clothing, such as gloves, in the belief that this creates an unacceptable barrier between them and their ailing family members. Social issues surrounding the stigma attached to HIV/AIDS and fear of isolation and alienation by the community also induce high risk behaviours of this nature.

Regardless of the fact that Botswana has recently been classified as a middle income country and that real per capita income increased from US\$ 300 in 1966 to US\$ 3.300 in 1999, the income poverty rate still stands at about 47% (Government of Botswana & UNDP 2000: 15). In addition, it has been projected that the AIDS epidemic will have a devastating impact on the Gross Domestic Product growth rate mainly due to the loss of skilled labour and increased government expenditure on health and social welfare services.

Home based care should be understood as part of the *continuum of care* a terminally ill patient is receiving. In the case of an AIDS patient, that would be from the time he or she is diagnosed with HIV, and the subsequent counselling, to nutritional advice and emotional support given in order to assist the person while living with the virus but not yet being ill. The care would con-

tinue when the person falls ill, ending only when the patient has died. However, a holistic understanding of care for an AIDS patient should also include the emotional support of family members or those who are close to the patient, including the provision of bereavement counselling. Home based care in Botswana needs to be understood as a government organised and formalised programme that has been in place for some time. According to the operational guidelines from the Ministry of Health, support given through government agencies should include counselling of patients and the family at home, material support to assist the carer, continuous visits by health staff, and a monitoring system that co-ordinates the work of the hospital, the clinic, welfare officers, community organisations, and the family. It also acknowledges that carers will need to be trained so that patients receive quality care and carers know how to protect themselves (AIDS/STD Unit 1996).

In some African countries people living with AIDS and their families have benefited from the creation of a continuum of care through the forging of links between patients, their homes, health centres, and district hospitals. In Zambia, Monze District Hospital has developed a community outreach programme including a strong element of support for patients and care-givers 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 (Altman 1994). In Uganda, one home based care programme has operationalised the concept of community based support networks comprising lay people, community leaders, and trained community AIDS workers to assist patients and care-givers (Kaya 1999).

Client and Carer Satisfaction with Home Based Care in Botswana

In reality, home based care in Botswana is faced with a number of serious challenges that prevent health care providers from offering the best possible care to those who have fallen ill with AIDS. One of the problems the country is currently facing is that at no time have People Living with HIV and AIDS (PLWHA) been involved in the planning of care services for terminally ill patients (who are, in the context of Botswana, mostly AIDS patients). Even though there are no comprehensive studies available providing data on client satisfaction and care-givers' perceptions on HBC, several smaller research projects have addressed these issues. The following discussion is based on two studies undertaken in March/April 2000 in Kweneng District, Botswana (Khan & Stegling 2000; Mojapelo, Ditirafalo, Tau, & Doehlie 2001).

Both of the studies mentioned earlier identified poverty as the main barrier to the provision of quality care to AIDS patients. In many cases, patients had

previously been employed and had contributed significantly to the income of the household. In the first study, of the 29 patients interviewed, 24 had been employed before falling ill, but at the time of the study only 2 were in paid employment. When asked what their main anxieties were, a great majority of patients voiced their concern about the future of their parents or young children after their death, while some were worried about the burden of care which they represented to their families. Many cited, as a major concern, the detrimental effect the disease had on the economic sustainability of the household.

While the government of Botswana provides food and material assistance for clients with terminal illness on home based care, such as a food basket, these services are not always utilised. Since almost all the patients interviewed in this sample denied being HIV positive, they did not utilise certain welfare services because of the stigma attached to these programmes. Their argument was that 'once you receive the food basket, everybody in the community knows that you are an AIDS patient.' Additionally, many patients were unaware of programmes available to them; for example, only a small minority was registered as destitute and the researchers found that, in many cases, only the care-giver was thus nominated, resulting in the entire family sharing one destitute portion which, under the best of circumstances, barely covers the basic needs of one individual (Khan & Stegling 2000: 12-13).

The findings of the second study concurred with those of the first in relation to the patients' experience of poverty; for instance, of the 30 patients interviewed, none was employed at the time of the research. The second study captures very clearly the feelings of patients once they had been discharged on home based care. Even though 39% experienced relief upon discharge, 21% described their emotional state as a feeling of helplessness, a statement that may have been related to the fact that four of the patients did not even have a care-giver when they returned to their homes. Poverty is identified not only by patients as a major problem. It is notably the care-givers who struggle to accommodate patients in a home environment often lacking in basic necessities. Of the care-givers interviewed in the second study, 85% were unemployed and often cited poverty as the main obstacle to the provision of quality care. As one care-giver pointed out:

I am suffering because I am poor. I do not have anything to support my patient and myself with. My patient was not working but was able to get a piece job occasionally and we were able to survive.

Another stated:

We need more food and soap. I do not have any clothes myself as well as my patient. We do not have a toilet, we use our neighbour's toilet.

Furthermore, many care-givers in this study felt unsupported by the extended family and health workers and were, therefore, uncomfortable with the task of looking after an extremely ill patient. Not only did they feel that health care providers were failing to supervise them in their care-taking activity, but also that they, as primary carers, were lacking in medical information to assist them in maintaining high standards of role performance. Below are some of their original statements:

We do not get any assistance from the health workers.

Health workers give us medication only. No other support is provided. Even if the patient is in a bad condition the hospital staff refuse to admit the patient.

My child did not want to be kept in hospital and I was very sad (Kautlwa botlhoko) because of the job involved in caring for the patient at home, cleaning and changing when the patient has diarrhoea. (Mojapelo, Ditirafalo, Tau, & Doehlie 2001)

Another indication of the inadequacy of the home environment is the lack of appropriate shelter. In the second study, two of the patients lived in old derelict houses while one lived in a plastic shack. These are obviously not places where the well-being of patients can be adequately supported. Additionally, as indicated earlier, of the 30 patients interviewed in the second sample, four did not have a care-giver and two were cared for by children, while three had 'care-givers' who were not capable of fulfilling this role due to old age or disability. Furthermore, as stated previously, it should be acknowledged that home based care is not provided by the entire family; in the great majority of cases it is provided by women. Of the 28 care-givers interviewed in the first study all were women, while in the second sample 89% were women. This gender imbalance in the provision of care needs to be addressed, especially since there are currently many voices calling for the greater involvement of men in the fight against AIDS in Botswana.

All these findings indicate that patients are referred home without adequate assessment of their domestic environment despite the fact that, according to the discharge plan utilised in hospitals, social workers should assess the social and economic environment of clients before they are referred (AIDS/STD Unit & WHO 2000). This should not be purported as critical of health workers, since the authors of this article acknowledge that health providers in Botswana are, in many cases, considerably overworked and that most health institutions are faced with a serious problem of under-staffing. In the case of social workers, the current staffing situation is more than dire with some pri-

mary hospitals employing one, or at the most, two social workers who are required to conduct all the pre- and post-test counselling in addition to facilitating the referral of patients to home based care. Therefore, the question under debate is whether the system is doing any justice to the increasing number of people falling ill with AIDS. Additionally, there is concern as to whether alternative and supplementary services should be offered to patients in order to maximise the quality of care and to allow for emotional and material support of care-givers and the wider family.

The authors of this paper assert that home based care, as currently implemented in Botswana, possesses unethical implications for patients and care-givers arising out of the system's unrealistic expectations of ordinary people, a great many of whom lack the knowledge, skills, and resources to realise the ultimate goal of home based care, which is to enable death to be experienced in a positive and caring environment of home, family, and friends. Both patient and care-giver (and, indeed, others involved in the situational context) are subjected to symptomatically and circumstantially induced trauma the like of which has not been experienced since the infamous Black Death and other plagues of historical significance, and, on a global scale, never before (Kelly 2001).

THE HOSPICE ALTERNATIVE

One solution to many of the problems associated with home based care in Botswana lies, in the opinion of the writers, in the holistic concept of the international hospice movement whose philosophy, perhaps somewhat ironically, affirms *life* rather than death through providing a place to live rather than to die. It exists to provide support and care for people in the last stages of incurable diseases so that they can live as fully and as comfortably as possible. The hospice concept embraces the belief that, through appropriate care (both physical and psychological) and the development of a concerned community and environment sensitive to the needs of patients and their families, both will be free to attain a degree of mental and spiritual preparation for death (Vancouver Hospice Project unpublished document, cited in Manning 1984).

The theme that unifies all hospice providers around the world is the desire to make available emotional, physical, and spiritual support to patients and their families/care-givers during the course of a terminal illness. In 1975 an international task force established guidelines for hospice programmes based on the following principles:

- Terminally ill people should be accorded control over the dying process.
- Treatment goals should take into account lifestyle and personal preference.
- Family and friends should be assisted in dealing with emotional, financial, and physical stress.
- Physical symptoms of patients should be controlled through programmes of pain relief.
- Hospice staff should be supported in coping with work related stress to help them sustain quality in the performance of their duties (Siebold 1992).

In practical terms, hospice offers services spanning a variety of perspectives and constitutes an ideal environment for an integrated approach to the needs of patients and their families through the co-ordinated efforts of, notably, pastoral, health care, and social work service providers.

Characteristics of Hospice Programmes

Special consideration in such programmes is given to specific factors that characterise the unique nature of hospice. It is the incorporation of these elements that demarcates hospice care from regular hospital services or home based care.

The palliative nature of hospice care focuses on relief from pain and suffering rather than on the curative aspect of treatment. Holistic control of pain and suffering is, in fact, the hallmark of the hospice movement, which espouses the belief that such control should be implicit in all treatment of terminal illness (Manning 1984). The objective is to improve the quality of life through relief measures and better preparation for death.

Demedicalisation of the processes inherent in illness, dying, death, and grief is an integral aspect of hospice service. Categorising conditions (and, by inference, related psycho-social factors) as diseases and pathological states and subsequently treating them as such does little to improve physical, mental, emotional, and psychological health (Siebold 1992). A holistic approach, with emphasis on people taking more responsibility for their own well-being and being supported in this by empathic service providers (including family members), is considered to be a true panacea for pain in all its forms.

In hospice terms, the patient is regarded not as a disease but as a human being experiencing fear, confusion, and anxieties that have to be dealt with in a humane manner by medical and other personnel as well as by care-givers. Open communication is deemed to be vital and, particularly in the residential unit setting, medical staff are always visible, approachable, and willing to discuss any subject that the patient is ready to confront. This is very different

from most institutionalised health settings and emphasises the hospice belief that the patient should remain in control of his situation at all times. Death is a stage in the process of personal growth and the dying person is living through the final stage of his/her human condition. During this period life offers the individual a last chance to grow and integrate all dimensions of their existence, to become more human, and to experience a sense of fulfillment (Manning 1984).

In hospice provision, the health care team, comprising the patient, the family, medical, and related staff (including social workers), and volunteers collaborates, through a co-ordinated, multidisciplinary approach, in the provision of quality care. There is a free flow of information and support between all participants and, significantly, even emotional involvement of medical staff with patients, a recognised taboo in traditional medical facilities. In fact, involvement of this nature is the very essence of hospice care (Manning 1984).

Residential hospice units are designed to be as much like home for patients as possible with as few aspects of institutionalisation as is feasible. Because of the nature of terminal illness, hospital-like accommodation might be necessary alongside the care and cluster housing model for those whose condition is not as debilitating. Culture and lifestyle are thus vital considerations in the design of residential services. Home care in ideal circumstances is the zenith of care for the terminally ill but, in many instances, circumstances are not ideal. The strain on families (especially women and especially those in Africa who are considered, unequivocally, to be the primary care-givers) creates an untenable situation for all concerned, including the patient. Even where circumstances in the home allow for quality care, residential hospice provision can be utilised in the short term to ease the sense of responsibility and the pressure on the family during episodes of poor patient health or simply to provide respite to care-givers. Day care programmes also supplement home based care and, where such facilities are attached to residential units, sufferers become familiar with the homely, comforting surroundings, and if admission becomes necessary, proves a less daunting step. There is, in other words, preparation for separation.

Education and training in the management of terminal disease is essential for medical staff who are involved in residential and home based care. Specific courses and in-service lectures, seminars, and workshops on relevant issues instil confidence and allow the staff to investigate their own inner feelings about death and to develop an openness to the feelings of patients regarding *their* mortality. In the process, reticent professionals are transformed into proficient listeners and carers (Kübler-Ross 1969).

An integral component in the process of education and training is supportive supervision of hospice workers and the formation of support groups as ve-

hicles for managing emotional reactions to the demands of the work. Feelings of loss and frustration are commonly addressed in fora such as these. "Working toward good death is rewarding, and it is professionally fulfilling to support one another, especially in sharing burdens and pains brought to the surface, as so often happens, with death and human suffering" (Krant 1974: 97).

Normalising grief is considered essential to enhance the coping mechanisms of families and care-givers. Bereavement and general counselling of family members begins before the death of the patient and is a vital component of hospice service. The human element of the environment, primarily family members and care-givers and *their* needs and feelings, is therefore a highly significant factor in the context of terminal illness and has to be addressed for the sake of the family, as well as that of the patient who might be grappling with a sense of guilt heightened by physical suffering and emotional distress (Manning 1984). Follow-up after the death of the patient is also part of the holistic hospice approach, with support groups for the bereaved playing a significant role in the healing process (Siebold 1992).

Holistic service provision allows for families to be actively and positively involved in (not overwhelmed by) patient care. Even in residential units relatives are encouraged to participate in psychological and physical ministrations to terminally ill family members. Culturally appropriate hospice type villages for families (especially those in which parents and some children may be suffering from HIV/AIDS) as have been established in some African countries, provide income generating projects and employment opportunities for sufferers and their families as well as educational facilities for their children. The concept of family strengthening is an important aspect of hospice service provision in all its forms (Chala 2001).

The welfare of children as patients has a special dimension in the hospice philosophy as childhood, in the natural order, signifies the beginning, rather than the end of life and its potential. Children's residential hospice units in the West provide short term respite or emergency care on behalf of families and care-givers and also permanent services where necessary. In countries such as those on the African continent where AIDS produces large numbers of orphans who may themselves be HIV positive, such units house and care for the children until their death in the belief that a loving, caring, and therapeutic environment prolongs and enhances the quality of life for a sick child.

Hospice in Botswana: Reality and the Road Ahead

Overall, the hospice philosophy incorporates the maxim of death with dignity. This concept arose in the West in the second half of the 20th century largely because of the impersonal, seemingly uncaring institutional approach

of large health facilities that prompted the rise of a social movement towards the dignification of the dying process (Siebold 1992). In Africa, death has traditionally been respectfully addressed in customary practice and managed with a high degree of community support and cohesion. The very nature of the AIDS epidemic has, however, denigrated the process and thrust patients and care-givers into dehumanising and degrading situations of physical suffering and stigmatising community response. The “death with dignity” campaign must now be waged on the African front with even greater vigour than in the West, taking into account the scale of the disease and the numbers of people both directly and indirectly affected.

The process has already begun. In Ramotswa (South East District) the Bamelete Lutheran Hospital’s hospice programme offers a day care facility for adults, providing opportunities for craftwork, companionship, mutual support, and enhanced nutrition. There is provision for home based care, an in-patient facility in the hospital, nondenominational spiritual care, and bereavement support. Resource persons include nurses, family welfare educators, and trained volunteers. Physical support for home based patient care embraces the provision of adjuncts such as medication, special mattresses, walking aids, and commodes (Kweneng District Multi-Sectoral AIDS Committee 2001).

The Holy Cross Hospice in the capital city, Gaborone, also has an adult day care centre and a home based care service, and organises a volunteer training and service programme. Plans are being formulated for the establishment of a residential unit, which will address the needs of the most serious cases for whom home based care is not a viable option.

The Thirisanyo Catholic Commission provides home based care in Mogoditshane Village on the outskirts of the capital, and is working with Rotary International, UNICEF, the Department of Social Work at the University of Botswana, and SOS Children’s Villages to establish a day care centre for pre-school children, an after care centre for school-going children, a recreation centre for out-of-school youth, and a residential facility for homeless children, all of whom are orphans and some of whom will themselves be terminally ill. A drop-in service for HIV positive adults is also being planned. The hospice philosophy is an integral component of this project and will complement its implementation and management. The programme will both employ and network with social workers in much the same manner as the existing SOS Children’s Villages in Gaborone and Francistown.

The North East District Multi-Sectoral AIDS Committee, under the auspices of the local authority, has established a day care centre specifically for PLWHA, which caters for approximately thirty people on a daily basis. There is pre-school provision for their children and a drop-in service comprising a counselling/resource centre. The committee has transferred the management

of the programme to a community based management trust, which has plans to establish a residential unit in the future. Similar initiatives are being undertaken by other district AIDS committees around the country. As many PLWHA are, in effect, homeless, consideration is also being given to the provision of so-called sheltered accommodation for those who require housing and a certain level of care but are not necessarily in the final stages of terminal illness.¹

Some districts, such as Kweneng, through their local authorities, are planning the establishment of so-called halfway houses, which will incorporate hospice principles in their service delivery. Notably, patients discharged from hospital to home based care will be accommodated for a period of approximately two weeks, during which time care-givers will be trained in methods of home care. The facility will also provide short term respite services and, in due course, residential care for those in the terminal stages of illness who lack family support, or whose care-givers require assistance (Kweneng District Multi-Sectoral AIDS Committee 2001).

It is the belief of the authors of this article that home based care requires support from government, communities, and non-governmental organisations such as hospice if it is to achieve its objectives. However, it is also our contention that supplementary and alternative services should be given high priority by policy makers and planners in Botswana without delay. Essential to the needs of the country is, in our opinion, the provision of culturally appropriate residential units throughout the country serving as many people as possible, especially those suffering debilitating and dehumanising symptoms (of HIV/AIDS or other terminal or chronic illnesses) and who live under impoverished conditions.

In such contextually relevant residential units or compounds, relatives will be encouraged to spend time with patients and become involved in their physical and psychological care. They will also receive counselling from social workers who will comprise an essential element of the permanent organisational structure, focusing on openness about the illness, the sufferers' feelings, significance of the response of families, and the patients' wishes in regard to their own condition and the future of their children, in particular. In some cases, relatives may be permitted to reside in the unit (especially if travelling distances are great) and arrangements could possibly be made for food to be available for at least one relative per patient. Work with families and outreach and networking services will also constitute an integral element of the social workers' practice. Family villages, as mentioned previously in this article, are another option and could incorporate care-giving of orphaned children by other families participating in the project. Once again, appropriately qualified

social workers would be required to co-ordinate and administer welfare services at all levels from a holistic perspective.

Voluntarism, as fostered in the Holy Cross and Bamalete Lutheran Hospice programmes and other home based care services throughout the country, should be encouraged in its purest sense, that is, without material remuneration where possible. Anecdotal evidence suggests that some “volunteers” in Botswana are mainly motivated by the, albeit small, material rewards they receive, which is a denial of the true spirit of voluntarism currently being promoted in the society’s war against HIV/AIDS. Some other African countries have a strong tradition of volunteer work, as evidenced by groups such as TASO in Uganda and the Family Health Trust in Zambia (Altman 1994). Student volunteers, popularly utilised in HIV/AIDS programmes in western countries, and others such as Thailand (Lyons 1992), serve the dual purpose of promoting a spirit of community in the youth and addressing the psycho-social needs of terminally ill patients and their families, and should be encouraged in Botswana. The role of social workers in state and non-governmental agencies, within the context of the development of voluntarism within the society, would be to engage in active recruitment and provision of group work services aimed at orientation and training of people of all ages with an interest in community service.

Related to the philosophy of hospice and indirectly aligned to its practice, is the fostering and adoption of children who are known to be HIV positive and thus terminally ill. Botswana is, at present, awaiting the implementation of regulations to the Children’s Act of 1981 (which is currently under review) on alternative arrangements for children in need of care, many of whom will be orphans of the AIDS pandemic and possibly infected with the HI virus. This legislation highlights the significance of the social worker’s role in the enhancement of adoption and formalised foster care procedures in Botswana with emphasis on *process* and the implicit need for growing numbers of qualified social workers in the provision of alternative care for children. Although the policy stipulates specific testing of children and potential care-givers only in the case of adoption (or permanency planning), where children are known to be HIV positive, adoption and fostering can be arranged in accordance with specific criteria, primarily the provision of in-depth training of alternative care-givers to prepare them for the vicissitudes of placements of this nature (Jacques 1998).

In many industrialised nations the voluntary or non-governmental sector, of which the hospice movement is a part, provides helplines, crisis intervention services, face-to-face counselling, support services for workers involved in HIV/AIDS issues, support groups for families and friends, appropriate housing, and other supplements to home based care. Botswana can and must

learn from such models, as indeed is already being demonstrated through the establishment of Lifeline, Childline, and other human rights agencies and programmes. Again, social workers already do, and will continue to, play a major role in the provision of services of this nature.

Policy initiatives for radical responses to the AIDS pandemic must have their roots in lobbying by interest groups at all levels of civil society while government has the responsibility of ensuring their translation into feasible legislative instruments. Social workers, as agents of change in society, play a leading role in this regard both at community and policy making levels. Similarly, financial resources for potential services discussed in this article will emanate from a variety of sources—the state, the private sector, local and international funding agencies, non-governmental organisations, and, possibly, beneficiaries of services themselves through the application of means assessment criteria. The latter procedure is necessitated by the fact that HIV/AIDS, terminal illness generally, dying, death, reluctant or absentee care-givers, and the desire for dignity in the final stages of life are no respecters of income and the ability or inability of clients to purchase services to enhance this period of their lives. However, the concomitant factors of loss of employment, inability to work, and reduction in household income increase the numbers of those requiring financial assistance.

Co-ordination of services and funding mechanisms and procedures are already proving problematic in Botswana's reactive and proactive response to the AIDS pandemic. There is a serious need for strategic planning in this regard with specific emphasis on means of monitoring and evaluation without which essential programmes will flounder and objectives, no matter how pragmatic, will fail to be achieved.

Social work practice, with individuals, families, groups, and communities, and at grassroots and strategic planning levels, will, we hope grow in stature and acceptance and develop a new dimension in a society steeped in the tradition of kinship and a belief in the efficacy of natural support systems. The HIV/AIDS epidemic is fast eroding structures such as these and there is a burgeoning need for professional social work recognition and input to adequately address society's changing demands.

CONCLUSION

The HIV/AIDS pandemic is wreaking havoc in the countries of sub-Saharan Africa, including Botswana, necessitating a variety of traditional and radical responses to stem the tide of the disease and ease the suffering of both infected and affected members of society. The situation in Botswana is, relative to population size, one of the worst in the world and, although awareness is high, specific

measures to address needs related to prevention and management are constantly having to be implemented to contain the problem on every front.

Home based care, while politically correct, expedient, and culturally relevant, embodies the germ of exacerbated human suffering for patients and care-givers alike unless rigorously controlled and generously supported through appropriate allocation of material and psycho-social resources. Social workers must be in the forefront of efforts to ensure that this is achieved. Additionally, as the Government of Botswana espouses the provision of universal health care as a basic human right, PLWHA should have the right to choose the care setting they prefer.

The philosophy and practice of the international hospice movement offers meaningful direction in programmes of care for the terminally ill in Botswana and other countries in the region. This is reflected in the Gaborone Declaration, which emanated from the First Regional Southern African Development Community (SADC) Home Based Care Conference held in the Botswana capital in March 2001. The theme of the conference, 'Sharing Responsibilities for Quality Care,' was addressed by delegates from ten SADC countries and the declaration represents consensus on essential principles as foundations for contextualised care of the terminally ill. Concepts include:

- Strengthened community participation and enhancement of the continuum of care.
- Recognition of PLWHA as key stake-holders in programmes of care.
- Improvement of the quality and duration of life.
- Support for care-givers (health care professionals and women).
- Creation of enabling environments through multi-sectoral networks.
- Sustainability of home based care programmes through community involvement.
- Empowerment of patients and families through provision of service options.
- Access to palliative care.
- Development of alternative models of partnerships and programmes.
- Enhancement of support systems.

All these concepts translate into hospice care through which, given political will, effective strategic, fiscal, and operational planning, and a visionary approach, African society may regain agency and once more dare to hope. Social work practitioners are an integral element in the vanguard of success.

NOTE

1. Light and Courage Centre, Francistown. Interview with co-ordinator, June 2001.

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