Community Home-Based Care in a Rural Village: Challenges and Strategies

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In Botswana, there has been an increase in community home-based care (CHBC) following a shift from hospital care to CHBC because of the HIV/AIDS epidemic. Yet the health care system has limited resources. To fulfill one of the terms of reference of the World Health Organization Collaboration Centre at the Department of Nursing, University of Botswana, an outreach program was developed in collaboration with 18 lay volunteers in a nearby village, Mmopane. This article discusses the process of establishing the CHBC committee and the challenges faced by faculty, students, and lay caregivers in working with a diverse CHBC group to render culturally sensitive care. Strategies for dealing with these challenges are discussed.

Keywords: *community home-based care; continuity of care*

BACKGROUND

HIV/AIDS in Botswana

Botswana is reported to have the second highest prevalence of HIV/AIDS in the world, with a prevalence rate of 17% (Central Statistics Office, 2004). The population of Botswana is 1.7 million, and the youth composes 44% of this population (Central Statistics Office, 2001). The youth (ages 15-29) have the highest rate of infection, accounting for the 56% of the reported cases of HIV in 1996 (Ministry of Health, AIDS/STD Unit, 1997). The effect of AIDS on the health sector was overwhelming (Lindsey, Hirsschfield, & Ncube, 2003). As the numbers of HIV/AIDS cases increased, the hospital bed occupancy rate increased from 65% in 1999 to 70% in 2003 (Lesetedi, Mukamaambo, & Shaibu, 2003; Motsa, 1999). The number of people on home-based care (HBC) has increased significantly with the increasing incidence of HIV and AIDS.

COMMUNITY HOME-BASED CARE (CHBC)

The CHBC Programme in Botswana started in 1994 and is guided by the National HIV/AIDS Strategic Plan (MTP II) that was developed in 1997 (Ministry of Health [MOH], 2001) and the draft National HIV/AIDS Strategic Plan (MTP III) that is currently in draft form. CHBC committees are that part of civil society response to the HIV/AIDS epidemic by nongovernmental organizations and community-based organizations (Lesetedi et al., 2003). The program was therefore seen as an important aspect of the Botswana health care delivery system and intervention strategy in the management of HIV/AIDS, given the shortage of nursing and other health personnel.

CHBC falls under a specific subunit of the AIDS-STD Unit, which participates in policy formulation on CHBC and coordinates CHBC activities. The objectives of the HBC program are

- To ensure optimum level of care for all terminally ill patients to avoid the dumping syndrome.
- To provide clinical care, nursing care, and on-going counseling services to both patients and their families at home.
- To establish functional referral system among hospitals, district health teams, and clinics and between districts.

HBC is defined as any form of assistance given to a person in need while at home. Most clients on HBC are the elderly or terminally ill patients.

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The care is provided by family and community members, with the support of skilled health and social workers who work as a team. The program attempts to satisfy four basic needs of the client: physical, psychosocial, spiritual, and material.

CHBC is coordinated at the national level by a national coordinator based at the AIDS/STD Unit. At the district level, the government has placed a HBC coordinator, assisted by nurses, a social worker, and volunteers. In addition, there are community health workers who provide services in homes. The HBC staff work in partnership with nongovernmental organizations, community-based organizations, community-based support groups, and volunteers (Lesetedi et al., 2003).

WORLD HEALTH ORGANIZATION COLLABORATION CENTER (WHOCC)

There are more than 35 centers that now form the Global Network of WHOCCs for Nursing and Midwifery Development, reflecting the WHO's view that midwives and nurses are at the forefront of the provision of primary health care in rural and urban settings. Three of these are in Southern Africa. The Department of Nursing Education at the University of Botswana was designated as a WHOCC for Nursing and Midwifery for Anglophone Africa in 1990. One of its current terms of reference is to establish a HBC model. This is consistent with fulfilling one of the goals of Botswana's vision for 2016. One of the pillars of Vision 2016 seeks to create a compassionate, just, and caring nation (Presidential Task Group, 1997).

Mmopane lies 10 kilometers away from the city of Gaborone and has a population of 5,000 people. It was selected as a clinical area for the WHOCC because of its proximity to the department. Permission to work with this village was obtained from the regional authority for this province and from the traditional authority, the chief.

CHBC COMMITTEE

Following a needs assessment of this village, the WHOCC worked together with the local community to establish the Home-Based Care Committee. Entrée into this community was negotiated with the chief and other relevant district and village authorities who also attended the first meeting. The first meeting was held at the *kgotla* (local meeting place) where the need for a CHBC committee was explained. Trust was established by winning the support of the village chief, whose approval is pivotal to the acceptance of any program. Involvement of the community in the development of health programs ensures the likelihood of success (World Health Organization [WHO], 2002).

The village's ownership of the program was encouraged to empower the community and ensure the sustainability of the program after the departure of the WHOCC from this community. Members of the community have a wealth of knowledge regarding their culture, environment, needs, likes, and dislikes and the causes of their ill health (WHO, 2002), and this was taken into consideration. The community was encouraged to take a leadership role while the nursing faculty and community health students facilitated the process of forming the CHBC. In an effort to provide culturally relevant care and encourage community participation, we worked very closely with community members.

A village meeting was called where the concept of a CHBC was explained to the people. Interested community members were given a week to think about the program, and interested volunteers were enrolled at the second meeting. Volunteers of a CHBC from a neighboring village that was selected by the MOH as exemplifying the best practice were invited to address the Mmopane volunteers on the process of establishing a CHBC. Other CHBC workers in the district were invited as resource persons to a seminar where the volunteers were given basic training on HBC and hygiene. The concept of using other volunteers in the region was used to motivate and empower the volunteers.

The WHOCC team ensured cultural sensitivity by bridging the gap between the community and ourselves through the provision of an environment that was safe for the community to share their needs and thoughts regarding the inception of a CHBC program. To ensure the success of the program, we ensured that the participation was voluntary. The chief urged interested parties to meet with us after we had explained the concept of CHBC at a meeting chaired by the him and held at the kgotla. Interested community members were invited to a meeting the following week.

At the second meeting chaired by the head of department, community members identified some learning needs and issues that needed to be addressed. Input from key community personnel is important as it assists faculty in the selection of experiences that are meaningful to communities (Baldwin, 1999). For instance, some volunteers belonged to churches that used alternative healing methods and wanted to know if they could join. They also expressed a need for clarification of their roles as volunteers. Their role was clarified as rendering whatever care they could such as bathing patients, assisting with cleaning the homestead, cooking, or doing whatever the client or family situation may require. They were also informed that over time they would be expected to give health education to families on various topics such as universal precautions, HIV/AIDS, and other topics that they could handle.

Volunteers mentioned that community members were concerned about family members whose AIDS diagnosis was common knowledge. They requested that confidentiality of clients' conditions should be observed. However they also mentioned that certain signs such as gross weight loss led community members to believe clients were infected with AIDS, as the disease was so prevalent that illnesses commonly associated with AIDS such as diarrhea were generally

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known by community members. Consultative meetings do not only yield valuable information but also serve as a public relations strategy (Moch, Long, Jones, Shadick, & Solheim, 1999). Over time we enrolled 18 volunteers, and 2 of these were male. Their level of education ranged from none to the basic 7 years of elementary education.

We also assisted the committee in drawing up a constitution so that they could be registered with the registrar of societies in the Ministry of Home Affairs. This was important as it enabled the committee to be eligible for funds that were availed to CHBC committees through the AIDS/STD unit. It also allowed the committee to open a bank account.

IDENTIFICATION OF CHBC CLIENTS

The concept of CHBC was still new, so we decided to obtain the list of chronically ill patients from the registered nurse (RN) at the health post as there was no discharge planning in place that ensured referral for continuity of care. As the list was not comprehensive, volunteers identified community-based, chronically ill patients who needed care through culturally established methods of communication. Volunteers were assigned to the wards (census tracts) where they lived, and the remote areas (traditional farms) were distributed among them.

STRATEGIES

Multilevel staff involvement not only provides more comprehensive perspectives but also enhances commitment to outcomes while reducing resistance to change (Barth, Mirvis, Hill, & Mulholland, 1999). In light of this, both volunteers and we as health workers negotiated strategies that would be employed for home visiting.

Entrée Into Family Homes

The CHBC volunteers advised us on the appropriate entrée into family homes. To establish trust, they identified ill patients in their respective wards (census districts) and approached families who were caring for an ill patient at home for their permission to visit the ill family member. It was very important that families granted permission to be enlisted on the CHBC program as many people were reluctant to be enrolled because of the stigma associated with CHBC. Although all chronically ill patients were eligible for enrolment in the CHBC program, at the time CHBC was associated with HIV/AIDS and its accompanying stigma. There was no telephone at the clinic, and many families with sick clients did not have telephones either, so contact had to be made physically.

Training

We assessed the volunteers' experiences with care of patients and assured them that we would do the initial home visits with them to illustrate how to do a home visit and render care at home. Prior to the home visits, a workshop for the volunteers was organized by the nursing department, and CHBC members were taught basic hygiene concepts and how to care for a family member at home. Use of HBC supplies such as gloves, diapers, and plastic waterproof linen protectors was demonstrated, as was disposal of waste. Guest speakers from well-established CHBC committees such as that from Gabane (nearby village) were also invited to come and share their experiences with the volunteers. The Gabane CHBC committee was one of the successful ones that exhibited best practices. Two RNs from the same district who were working with CHBC committees and the chief also attended.

As there was no electricity in the village, and because of the small size of the health post, we decided to do the next training session of volunteers at the University of Botswana in the nursing arts laboratory. The training of volunteers this time was done together with community health nursing students who had been working with the volunteers and had identified their learning needs. In addition to the training session, we had small focus group discussions with the volunteers where they were able to evaluate the CHBC program. After the training session, they informed us that they could not carry out some activities that we had taught them such as bed bath as that was intimate care that was preferably done by family members.

Home Visits

We demonstrated to all the volunteers how a home visit was conducted. We worked together and took the lead where the visit mostly demanded clinical care and health education. The community volunteers took the lead with respect to entrée into the family. We illustrated how care should be rendered and how care should be documented. Sometimes during the home visits, we were confronted with patients who had social issues that left us as professionals at a loss, short of requesting the social welfare officer to attend to such issues. The community members or volunteers did exceptionally well in solving some of these social issues or mobilizing the necessary community resources to attend to the problems that we would have normally referred to the social worker. This way we also learned problem-solving strategies from the community and always acknowledged their strengths.

Community volunteers were also instrumental in highlighting family dynamics underpinning some complex cases. For example, some families believed that the illness was caused by witchcraft. This was always useful in planning care as it enabled us to take into consideration the family background in cultural repatterning strategies.

CHALLENGES

Several problems faced the implementation of the HBC program. These included acknowledging the indigenous health care, shortage of staff, transportation, lack of docu-

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mentation, discharge planning, remuneration, and poverty. For students, loss of control seemed to be the main problem as some had difficulty granting patients their autonomy in their homes.

Shortage of Staff

Human resource constraints is a setback to the program. There is a shortage of RNs and social workers. Social workers cover a wide area, and consequently some patients die before they can be attended to by the social worker who could have assessed their eligibility for food baskets. As a result, although the material support resources (such as food, gloves, linen protectors, aprons, antiseptics) are available, the distribution of supplies among identified deserving cases is constrained by this very shortage of human resources.

There is no RN at the health post who is assigned to work directly with the HBC committee. The RN who is stationed at the health post has to extend her role to cover the HBC activities on a regular basis in a community where there is no vehicle available for the health post. The RN who is supposed to oversee the activities of this HBC committee is responsible for several villages, often of a radius of 50 kilometers.

Transport

The lack of transportation posed problems for both the volunteers and the trained staff. The health post did not have any vehicle that was attached to it. Consequently, those patients who lived in the remote areas of village surroundings such as areas preserved for agricultural produce on which the community survives could not be easily reached. Occasionally the university transport was used to access those patients who lived in distant places. This meant that only patients who were within easy reach could be enrolled in the CHBC program. Yet an adequate means of transport is pivotal to gain access to comprehensive CHBC (WHO, 2002).

Referral System

There is lack of coordination from the referral hospitals to the HBC committees. Subsequently, there is no continuity of care as patients are discharged home without any liaison between the hospital and the HBC committee. Patients are enrolled into the HBC as their needs demand it through case finding by the family welfare educators, the volunteers, or the locally based RN at the health post. Sometimes the relatives seek assistance from the health post when faced with overwhelming demands of HBC following the discharge of a relative from hospital. Although generally there is an awareness of the CHBC program, there is no network of resources and services that ensure continuity of care as patients move back and forth between health services.

Documentation

There is no official form used for documentation of HBC. Instead, nurses used the patients' outpatient cards to document care. However as some of the volunteers were illiterate, we requested that they report what had transpired during their home visits at their weekly meetings. This was documented at their weekly meetings by the secretary and at least provided a record of the activities that had been performed in the homes. It also was a way of giving each other feedback on activities rendered. Documentation of HBC activities is problematic as some volunteers are illiterate and some function at low literacy levels. Most volunteers in developing countries have limited education, and their literacy should be treated with sensitivity (WHO, 2002). A form for documenting CHBC activities is still being developed by the AIDS/STD unit. Otherwise, to date, RNs record activities on the regular hospital cards.

Remuneration

Volunteers were given a monthly allowance of one hundred pula (US$20) to offset their travel expenses. Although this is a pittance allowance, it did help with transport costs. Initially not all volunteers could be paid this allowance because of the limited funds available to the district. Consequently some volunteers were discouraged by what they termed an unfair practice, and some attended reluctantly and irregularly. Over time, this allowance has now been granted to all volunteers.

Poverty

Although the government provides food rations for the HIV/AIDS patients on CHBC, unfortunately some patients who are eligible for these food baskets die before they can receive them. A lot of families with patients on HBC were steeped in poverty. Initially this seemed to preoccupy the volunteers, who then decided to engage in fundraising activities such as gardening and beadwork. The money raised was initially used to assist bereaved families with funeral expenses. However the funds raised were so meager that the volunteers were unable to cope with assisting families in this regard as more patients on CHBC seemed to die before enough funds could be generated. It was then agreed that the money would be used to assist families who were in dire need of food for the patients.

When health care shifts into the home, limited resources and stretched client care services may divert the focus of care from patient welfare concerns to resource allocation (Selin, 1996). We encouraged the volunteers to focus more on client welfare. Client advocacy on our part was then very important as we encouraged the volunteers to focus more on patient care. At some times it seemed volunteers were spending more time on beadwork (to raise funds) than on visiting patients. Funds were used for emergency spending on those families who had no food. However as the CHBC committee gained momentum, they received donations such as five thousand pula (US$1,000) from the Botswana teachers union and money from individuals, commercial banks, and other inter-

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national visitors such as Professor Holzemer and his team. The local land board donated a piece of land next to the health post where the CHBC volunteers are now located.

Stigma

CHBC has come to be associated with HIV/AIDS. Consequently, some families who need the services of the CHBC program refuse to have their family members enrolled because of the fear of the stigma. Even those patients who were not HIV positive refused to join the program. A case in point is a hemiplegic patient who refused to be enrolled in the CHBC program in spite of being told that the enrollment would, among other benefits, provide him with a wheelchair. Some of the challenges that we have yet to overcome are the stigma and the convincing of communities that CHBC is for all chronically ill patients. The theme for the 2002 World AIDS Day was stigma and discrimination, and although this has been discussed in many fora, it is still a problem.

Loss of Control

Some patients at some point abandoned Western biomedicine for traditional or other alternative healing methods. Some students had difficulty dealing with situations such as this. One graduate student literally threatened to sue one such traditional healer. This particular student had been working with this patient for about 3 months and had been nursing him for several opportunistic diseases. On this particular occasion, the patient had pneumonia and would not take his antibiotics. The caregiver pleaded with us to convince him otherwise, but initially he would not agree. Finally I called one of the senior church members who was also the chairperson of the CHBC committee and asked her to talk to him. After a long discussion, he was convinced to continue with both treatments, the herbal tea treatment from his church and the antibiotics. Our cultural brokerage and cultural accommodation roles and skills grew over time.

Although autonomy of clients and families who are based in the community had been discussed in class, it seemed students had problems with locus of control when it came to the real world. Some families or clients would tell us to go away or that they simply changed their minds about the treatment they were on. Students found this very frustrating, especially when they knew the patient had HIV/AIDS and that there really was nothing that the traditional healer could do for them. Over time we taught students cultural repatterning strategies by encouraging them to meet and negotiate with traditional healers regarding treatment. For instance, in cases where a traditional doctor would need to administer an enema to a dehydrated patient who already had diarrhea and vomiting, students would persuade him to postpone it until a later date when the patient's condition would be able to sustain such a treatment.

DISCUSSION

There were several accomplishments in spite of the many challenges that confronted the CHBC program in Mmopane. The Vision 2016 goal of achieving a just, compassionate, and caring nation (Presidential Task Force, 1997) is being realized as volunteers go out of their way to provide care to patients in their homes. More volunteers have been enlisted since the inception of the program. We started with 12 and now have 18 volunteers enrolled. The level of awareness has been raised in the community with respect to self-reliance and what the CHBC program is about. The CHBC program assists in health education as a lot of teaching happens in the home. Rendering care at home assists the faculty in providing family-centered care, which is the clinical approach adopted by the nursing department.

Working with this community provided an opportunity for cross-cultural learning for both faculty and students. We learned how the community operated and also to tailor our logistics of enrollment to the operations of the community, hence making care culturally relevant and sensitive. For example, one day we used the university vehicle to visit an old lady who lived in the distant fields. As vehicles only reached some of these remote places in the event of an emergency such as a family death, the old lady was frightened by our visit. After this experience, the volunteers suggested that we should develop new ways of alerting the families about our visits so that we would not unnerve them unnecessarily. According to de Villiers and Tjale (2000), rendering culturally congruent care rests on the principles of knowledge, respect, and negotiation. Over time we learned to render care in a culturally appropriate manner by learning, accepting, and respecting the culture of the community.

Although the volunteers sat through classes on basic care of an ill patient such as bed bathing, they informed us that intimate care was really the prerogative of families and that most families would not allow them to assist with that. Most families in Botswana, even if they use a hired helper to assist with chores in the home, leave the intimate care to close family members (Shaibu & Wallhagen, 2002).

The volunteers found the high rate of people dying of AIDS emotionally draining, yet there were no counseling programs in place to assist them in dealing with this loss. Providing volunteer support and care is essential in the recruitment and retention of volunteers (WHO, 2002). As government continues to employ counselors who are based in clinics, counseling services will be made available to volunteers and other team members of the CHBC program.

The volunteers and community have celebrated successes as the CHBC committee became recognized. For example, donation of funds by community organizations is usually a celebrated occasion where community members, village authorities, and district-level authorities are present. This also gives good publicity to the CHBC program.

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IMPLICATION FOR NURSING PRACTICE

Clearly from this experience, we came to appreciate that the politics of the setting are very important to the success of any program. The support of the chief was instrumental in the success of the program because the chief is of unique significance in a traditional society in that he is perceived as a father figure, above politics, and a repository of cultural folklore. Although there are guidelines for the training of the home-based volunteers, cultural issues should always be taken into consideration. Cultural competence on the part of the health workers who work with volunteers is key.

The literacy level of the volunteers should always be considered in developing teaching materials. As groups can have diverse literacy levels, this can require a lot of innovation on the part of nurses. There is need for discourse among the health care workers, CHBC teams, and traditional healers.

CONCLUSION

The human resource aspect of CHBC needs to be improved. The availability of more social workers would assist in the alleviation of poverty found in some homes with CHBC patients. No HBC program can provide quality care if the family is steeped in abject poverty. Therefore the provision of food to needy patients is crucial. Some patients refrained from participating in the CHBC program, and although they needed the food baskets, they refrained from receiving them because of the stigma attached to the CHBC. Therefore stigma remains an impediment to the CHBC program (WHO & MOH, 2003).

CHBC assumes that families have the capability to care for patients. Often families do not always have the resources such as social support and material support to care for their families in the community. This collaborative venture with community members was a venture that empowered the community members, students, and faculty through experiential learning. Students came to appreciate the complexities of nursing from a population-based perspective. Although there are some problems associated with CHBC, several achievements have been made and celebrated.

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