

HOME-BASED CARE IN BOTSWANA: EXPERIENCES OF OLDER WOMEN AND YOUNG GIRLS

Elizabeth Lindsey, RN, PhD

University of Victoria, Sidney, British Columbia, Canada

Miriam Hirschfeld, RN, PhD

World Health Organization, Geneva, Switzerland

Sheila Tlou, RN, PhD, and Eiphram Ncube, RN, MN

Faculty of Nursing, University of Botswana, Gaborone, Botswana

In this exploratory and descriptive study we investigated the experiences of and impact on young girls and older women caring for family members living with HIV/AIDS and other chronic and terminal illnesses at home in three districts of Botswana. Using qualitative research methods, we conducted 70 interviews with family caregivers and key informants such as community home-based care (CHBC) team members and government officials. Older women reported feeling overwhelmed with the magnitude and multiplicity of tasks they had to perform. They reported feeling exhausted, malnourished, depressed, and often neglectful of their own health. Young girls often missed school and they were sexually and physically abused, sexually exploited, and depressed. In addition, these caregivers experienced poverty, social isolation, stigma, psychological distress, and

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Address all correspondence to E. Lindsey, Professor Emeritus, University of Victoria, 8590, Emard Terrace, Sidney, BC, Canada, V8L 1K4. E-mail: snooky3@attglobal.net

a lack of basic caregiving education. We made recommendations to improve services and care to the CHBC teams and to the national government.

We interviewed a grandmother (age 56) caring for her daughter (age 32) and granddaughter (age 11), both living with HIV/AIDS. This diagnosis was clouded in secrecy. The community health workers thought the child contracted the virus through sexual abuse; however, this could not be confirmed. The child had oral and oesophageal thrush and tuberculosis (TB), and her mouth was bleeding. She was very emaciated and complained of painful swollen legs. Her mother was also wasting and lethargic. Two other family members had already died of AIDS. This caregiver provided physical care to her granddaughter such as bathing, feeding, and helping her to the pit toilet. The mother was able to care for herself at the time of the interview. The grandmother also described how she collected wood and water from the standpipe, cooked, and did all the other household tasks. In addition, she took care of her brother's two orphaned children. She explained:

I don't really understand what is happening to her (the granddaughter). If I am not around, no one can cook for her or assist where help is needed. I make sure she has enough blankets and I heat the water and bathe her each day. My heart is always painful and I do feel like crying. . . . I am the one who is responsible for anything that arises.

We investigated the experiences of and impact on primary caregivers caring for family members living with HIV/AIDS or other chronic and terminal illnesses at home in three Botswana communities. We focused on the impact of caregiving on older women and young girls. The specific purposes of this study were to (a) explore and describe the phenomenon of giving home-based care to family members living with HIV/AIDS and other chronic/terminal illnesses; (b) raise awareness of home-based family caregiving, particularly in relation to forgone opportunities for a satisfactory quality of life for older women and young girls; (c) develop sustainable effective interventions to improve the quality of life for these home-based family caregivers; and (d) develop sustainable effective interventions to improve the quality of care for persons living at home with HIV/AIDS and other chronic or terminal illnesses.

CONTEXT

The study was conducted in Botswana, a landlocked country boarded by Namibia, Zambia, Zimbabwe, and South Africa. With an area of

582,000 square kilometres and a population of approximately 1.5 million, the country is sparsely populated. Setswana is the national language, with English the official language of government.

Botswana has benefited from a stable social structure and a wealth of natural mineral resources. It has had an unbroken record of parliamentary democracy and one of Africa's highest sustained records of gross national product (GNP) growth since independence in 1966. In fact, Botswana is among the few African countries classified as "upper middle class" (Medium Term Plan [MTP] II, 1997–2002, p. 5). Botswana has a publicly funded education and health care system. Primary and secondary education is free, with adult literacy at 70% (MTP II, 1997–2002). Primary health care (PHC) is predominantly free and universally free for children, pregnant women, and TB patients.

Despite Botswana's relative affluence, 47% of the population live in poverty, with 62% living in rural areas and 38% in urban settings. Of note is the high incidence of female-headed households (47%), with the majority of these households living in poverty.

HIV/AIDS in Botswana

Botswana is reported to have the highest prevalence of HIV/AIDS in the world (Ngcongco, 1998). Young people (ages 20–45), those most sexually and economically active, are most affected. Forty-five percent of the population is between the ages of 15 and 49 years, and this age group accounts for 89% of reported HIV cases. Youth (15–29 years) have the highest rate of infection, accounting for 56% of the reported cases of HIV in 1996 (MTP II, 1997–2002). The AIDS/STD Unit, Ministry of Health (1998) indicated in the Seventh Sentinel Surveillance in Botswana that out of 4,194 pregnant women tested in Botswana, 33.5% were found to be HIV seropositive. To compound this problem, 67% of HIV cases are reported to have TB as a coinfection. It is estimated that by 2000 there will be more than 65,000 AIDS orphans (Modungwa, Selelo, & Doehlie, 1999).

Community Home-Based Care (CHBC)

The impact of AIDS on the health sector is great. The AIDS/STD Unit, Botswana Ministry of Health in the Medium Term Plan II for Botswana (1997–2002) reports that 50% of the beds in the medical and paediatric wards of the two major referral hospitals in Botswana are for patients with HIV-related illnesses. In addition, Motsa (1999) reports that 65% of hospital beds throughout the country are now occupied by people living with HIV/AIDS (PLHA). CHBC is seen as a key strategy to sharing this

burden of care among hospitals, clinics, health posts, families, and the community (Mathebula, 2000).

A CHBC program has existed in Botswana since early 1990 (Mathebula, 2000). CHBC is defined as

care given to individuals in their own natural environment, which is their home, by their families; supported by skilled 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/AIDS including all other chronically ill patients, social welfare officers including nurses (who will play the lead role), social workers, district health and nutrition officers and other allied health professionals. (AIDS/STD Unit, Ministry of Health, 1996, p. 3)

The rationale for the implementation of CHBC in Botswana is that it is the best method to care for many people with terminal illnesses. The goals and objectives for CHBC are to prevent HIV transmission and to reduce the impact associated with HIV/AIDS on those infected and affected (AIDS/STD Unit, Ministry of Health, 1996).

Various evaluation studies have been conducted in different districts in Botswana (AIDS/STD Unit, Ministry of Health, 1998; Ngcongco, 1998). These studies provide important insight into the issues related to CHBC and speak to the overall efficacy of the programme.

THE STUDY

This study was part of a larger research project funded by the World Health Organization (WHO) to investigate CHBC in resource-poor settings. The primary purpose of this investigation was to gain a greater understanding of the issues and concerns of family caregivers providing care at home. The ultimate goal of the larger research project was to make recommendations and suggest strategies for developing and sustaining effective CHBC in resource-poor settings.

The study was exploratory and descriptive, using qualitative research methods. Background information on demographics, illness and treatment variables, and support resources were collected. We explored the actual work of caregiving, including direct physical and emotional care, management of symptoms and medical regimens, as well as the performance of surrogate roles by the caregiver. We also collected data on the impact of caregiving by older women and young girls. Such data included the effects on the caregiver's physical, mental, social, and developmental well-being, as well as on their health and financial status. Finally, questions were raised to explore strategies that might support

family caregivers and the actions that could be undertaken to implement these suggestions.

We hoped that the findings of this study would form a catalyst for action toward reducing the impact on family caregivers and enhancing their quality of life. As such, this research incorporated the philosophy and processes of action research (McTaggart, 1993). Action research is a cyclical process toward effective action, in which empirical decisions on the research topic and action embedded within the research (including continuous evaluations) are conducted (Wadsworth, 1997). This cyclical process of action research was actualised by the constant reporting of findings to members of the CHBC team. For example, when a caregiver and her family were deemed to be living in extreme poverty, the social worker was informed and an assessment for destitute allowance was conducted. Another example was the need for supplies. When the research team learned that supplies were needed, a request was given to the CHBC team and action was taken. Sometimes research team members also participated in supply provision.

At the end of the study, the principal researcher provided a verbal and written report to members of the Ministry of Health responsible for CHBC. Gaps in services were identified, and issues related to the impact of providing care to family members at home were discussed. It has been reported recently that some actions have been taken based on this verbal and written report.

Population and Sample

The population was a convenience sample (Morse, 1991) of primary caregivers of PLHA and other terminally/chronically ill family members at home. In addition, key informants such as CHBC volunteers, family welfare educators, nurses, social workers, and members of nongovernmental organizations (NGO) involved in CHBC were included in this study. Finally, data were collected from personnel from the Ministry of Health and researchers and consultants involved in issues related to CHBC.

This study was conducted in three districts within 120 kilometers of Gaborone, the capital city of Botswana. Two rural districts included Kweneng (population 180,000) and Kgatleng (population 40,000–50,000), and an urban district of Old Naledi (population 20,000–30,000), a suburb of Gaborone.

Data Collection

Members of the University of Botswana research team, personnel from the Botswana WHO Regional Office, and members of the Ministry of

Health suggested the CHBC sites to be visited. The Botswana researchers then contacted nurses at these sites and requested their participation. This request was granted. In turn, the nurses at each site suggested families that could be interviewed. A community health worker then visited the families and requested permission to interview them about their experiences of providing care to ill family members at home. In this way, informed consent to interview caregivers was obtained. Potential respondents were informed of the purpose of the study and the data gathering method and were assured privacy and confidentiality. It was stressed that caregivers who wished to decline would not experience negative consequences to their care. No caregivers refused to participate. Members of the research team obtained informed consent (including issues of confidentiality) from key informants. Again, none refused to participate in the research.

Two interview guides were generated: one for caregivers and the other for key informants. The caregiver questionnaire focused on the experiences and perceptions of caregivers in caring for ill family members at home. This questionnaire was written in English and translated into Setswana. Research assistants interviewed the family caregivers in Setswana and wrote the caregiver responses onto the questionnaire in English. Thirty-five caregiver interviews were conducted in this manner. The second guide (conducted in English) consisted of open-ended interviews with 35 key informants, including nurses, family welfare educators, social welfare officers, CHBC volunteers, and other stakeholders in CHBC and HIV/AIDS care. These interviews were either tape recorded and transcribed, or notes were taken directly onto the questionnaire. Seventy interviews were conducted.

Research Integrity

The research team consisted of members from the University of Botswana Faculty of Nursing and research assistants from the Society for Women Against AIDS in Africa, Botswana Chapter (SWABO). Logistical research arrangements were made between the principal researcher and project manager from WHO and the University of Botswana researchers. The principal researcher undertook overall management of the research project in Botswana; however, this researcher could not speak Setswana. As a consequence, the research team was very sensitive to issues of translation, observation, and knowledge of local customs and practices. For example, the principal researcher visited all the study sites and many of the homes. Once introductions were made, the principal researcher left the compound and a member of the research team conducted the interview. At the end of each day the research team would discuss issues related to data collection and contextual understanding.

The principal researcher conducted most of the key informant interviews. However, it was considered necessary to hold team meetings to discuss the preliminary findings from these interviews. Through discussions meanings could be further elaborated and certain contextual issues clarified. Finally, a draft copy of this report was sent to the research team for their confirmation, elaboration, or correction. In this way, the research team paid particular attention to cultural, traditional, contextual, and semantic issues related to the research.

In keeping with qualitative research methods, the purpose of determining sample size was to reach redundancy or saturation (Morse, 1994) of the data. After 15 interviews with caregivers and 12 interviews with key informants, the issues presented in this study had been identified. The remaining interviews provided elaboration and confirmation of the results; however, no new substantial information was obtained. It was therefore deemed that redundancy and saturation was achieved.

Data Analysis

Data were analyzed using qualitative research methods. The caregiver interviews were analyzed using content analysis (Manning & Cullum-Swan, 1994). Each question was coded and these codes were later combined to provide categories of responses with some numerical components. These categories were further refined and incorporated into research themes. For example, caregiver age, number of years providing family caregiving, and the number of hours of caregiving activities each day were recorded. These numbers were later incorporated into research themes.

The key informant interviews were analyzed through thematic analysis (Huberman & Miles, 1994). Interviews and transcriptions were first read to get a sense of the data as a whole. Units of meaning relevant to the research questions were then identified and coded into early themes. These themes were then combined with the caregiver interview codes. Finally, patterns and metathemes that exemplified the perceptions and experiences of family caregivers were identified.

RESULTS

First, the demographic variables of the caregivers will be provided. This will be followed by the illness- and treatment-related variables. Finally, the impact of providing care to a family member with HIV/AIDS and other chronic or terminal illness at home will be presented.

It is interesting to note that although caregivers were caring for family members with HIV/AIDS and other chronic or terminal illnesses, the

experiences of these caregivers appeared to be similar. However, this research did not endeavour to compare the experiences of providing care to PLHA and those with other chronic or terminal illnesses. Therefore, any suggestions as to why the experiences appeared to be similar can only be speculated. It was thought that the stigma associated with home-based care might account for this finding. Also, it was noted that the patients not diagnosed with HIV/AIDS had severe chronic or terminal illnesses. Suggestions were made that the seriousness of these illnesses might account for the similarities in caregiver experiences. However, these possible reasons are merely speculation.

Demographic Variables of Family and Primary Caregivers

Fifty-four percent of the caregivers ($n = 19$) were 54 years or older and 72% ($n = 25$) were single. Sixty-six percent ($n = 23$) of the households were headed by women. The vast majority of the caregivers had little or no education (57%) and their socioeconomic status was predominantly low (57%). Only 4 caregivers had employment outside the home, with 2 having only temporary employment. The elderly in Botswana receive 110 Pula (approximately \$26 U.S.) a month. This pension often was the only source of family income. If a family was assessed as destitute, rations and other material goods were available from the social welfare officer. In many instances, other family members contributed to the household. This contribution was usually in the form of food and was not always available.

Mothers (12) were the most common primary caregivers, followed by grandmothers (7), sisters (7), and daughters (5). There was also 1 husband, brother, uncle, and 1 daughter-in-law acting as a primary caregiver. That is, of the 35 caregivers interviewed, 32 were female and 3 were male. The researchers did not stipulate that caregiver interviews should be conducted with women only. They were interested to ascertain how many male caregivers would be identified within the communities and whether there were differences in caregiving experiences and activities between the male and female caregivers. Although the vast majority of primary caregivers were female, there appeared to be no differences between the experiences and activities of the male and female caregivers.

ILLNESS AND CAREGIVING VARIABLES

Of the 35 caregivers interviewed, 15 were caring for 1 or more family members with HIV/AIDS and 20 were caring for a family member with another chronic/terminal illness. It is interesting to note that the CHBC

teams stated that the majority of their patients had HIV/AIDS, yet it was difficult to interview these caregivers and no firm numbers of patients with HIV/AIDS were given to the research team. It appeared that patient confidentiality precluded the researchers from knowing this information. In Table 1 we provide an overview of the illnesses being cared for by caregivers.

When asked how many hours the caregivers devoted to caring for their sick family member, 21 (60%) said they devoted more than 12 hours of care each day, while 6 said their caregiving took up to 6 hours, and 8 caregivers reported their caregiving took minimal time. The caregiving activities included both personal care, such as bathing, feeding, dressing, mobilizing, and helping with elimination, and so on, and instrumental activities of daily living, such as collecting water and wood, cleaning, obtaining health supplies, shopping, cooking, and dealing with finances.

Quality of life was measured using a 5-point Likert scale, with poor rated as 1 and excellent rated as 5. Twenty caregivers (57%) reported their quality of life to be poor, while 9 (26%) stated it was neither good nor bad, and 6 (17%) considered their quality of life to be good.

A second 3-point Likert scale was used to rate the impact of caregiving, with 1 rated as low and 3 as high. Twenty-six (74%) caregivers stated the impact was high, while 4 reported a medium impact on their lives, and 5 considered the impact to be low. Interestingly, although most caregivers considered the impact of caregiving to be high, the level of satisfaction in their caregiving role provided a somewhat different story. Nine caregivers (26%) stated that they were satisfied with their caregiving role while 7 (20%) were moderately satisfied, and 13 (37%) rated their satisfaction as low (6 nonresponse). The caregivers who rated their satisfaction as high made such comments as, "She is my daughter, I want to care for her all that I can."

Table 1. Illness-related variables ($n = 35$)

Illness	Number of patients
HIV/AIDS	15
Cardiovascular disease	8
Cancer	4
Cerebral palsy	2
Severe arthritis	2
Epilepsy	2
Head injury	2
Total	35

THE IMPACT OF CAREGIVING

The following section identifies the themes that emerged from the interviews with caregivers and key informants that exemplify the impact of family caregiving in home-based care. First, the impact on older caregivers will be presented. This will be followed by the impact of caregiving on young girls. Finally, general issues related to caregiving will be presented. These issues include (a) poverty, (b) isolation, (c) stigma, (d) lack of knowledge, (e) the need for psychosocial support, and (f) the role of traditional medicine.

Elderly Women as Caregivers

Older women should be able to relax and enjoy the fruits of their labour. They expected to depend on their children; now they are having to care for their children, which is an unexpected role change. (Nurse respondent)

The overriding experience for older women was exhaustion ($n = 56$). As one nurse explained, "They need to be the ones in bed." Often the caregiver was caring for more than one sick family member and many caregivers were also caring for orphans. There were examples of elderly caregivers having to collect wood and water, make the fire, cook, shop, do laundry, clean the house and compound, tend the garden and arable lands, and travel to the health clinic for medications and supplies.

The actual caregiving activities were reported also to be very taxing. Caregivers described caring for family members with incontinence, diarrhoea, vomiting, confusion, skin lesions, and suffering pain. Caregivers talked of feeling overwhelmed with all the responsibilities that had been thrust upon them ($n = 26$). One mother described her experience of caring for her son: "I am the one responsible. It really impacts because he can't get better and is getting worse, time and again. My heart is always paining."

Although the caregivers were advised on the use of universal precautions, very few caregivers heeded this advice ($n = 2$). As one caregiver explained, "It is my daughter, I love her. I can't wear gloves or other things. If I am holding or nursing my child I love, putting a barrier would be like I don't love her."

Respondents also reported that elderly caregivers experienced depression ($n = 28$) and personal neglect ($n = 36$). Malnourishment was a common concern ($n = 61$). These caregivers would feed the family and the sick person first, and often there was no food left for them. As one caregiver explained,

I get depressed. Caring makes you stay in constant emotional pain. I am always praying to God for a cure of healing. I am always tired. Sometimes

I can't even wake up to help her. I really need more help. Your spirits become too low because we see young people dying and we don't know what the young people are dying from.

As a result of AIDS the extended family was reported to be disintegrating. Many of the traditional roles undertaken by different family members were no longer possible. Men used to tend the cattle and plough, seed, and harvest the crops. These men are now often too ill to perform these tasks, or they are already dead. In addition, many of the young mothers have HIV/AIDS, as do their children. As a result, older women take on the caregiving role for the extended family, including orphan care.

Many caregivers found religion to be a comfort ($n = 20$). They explained that their belief in God had been strengthened as they tried to understand the impact of the illness. One caregiver explained: "I have even more hope in God. He is the comforter and I put all to God." Another caregiver said, "I still trust in God and getting help from my ancestors." However, other caregivers stated ($n = 6$) that they had no time to go to church and they no longer worshiped at home.

Young Girls as Caregivers

Only 2 young people were interviewed about their experiences as primary caregivers. This was because most children ($n = 33$) did not play a primary role in caregiving. Instead, they played a supportive role to primary caregivers and were not home at the time of the interviews. However, young people's caregiving roles were well documented by key informants. One nurse noted:

Girls are the first to be taken out of school. It is a custom for the girl child to help when the burden gets too much. They often have to care for the grandmother, the sick parent, and other siblings. They miss school.

If young girls attended school, they rarely had time for homework and often had difficulty concentrating due to malnourishment and exhaustion. As a consequence, bright children became poor students and many left school. These young people were socially isolated, with no time to play or engage in other age-appropriate activities. In addition, as these girls dropped out of school, their opportunities for future employment were compromised.

Young girls were also reported to experience psychological trauma and depression as they watched their parents and other family members dying from AIDS. They described young girls living with no hope and a sense of despair, "living in constant fear of losing a loved one." Key informants also reported problems of physical and sexual abuse. Three children in the study were thought to have contracted HIV as a result of familial sexual abuse.

Issues of poverty had considerable ramifications for young girls. One way young girls sought to alleviate poverty was to sell their bodies for sex to older, wealthier men. There were examples of young girls engaging in sex for money or other material goods ($n = 15$). Often family members were aware of this activity, but they were so grateful for the small material advantages that they chose to ignore the behaviour. As a member of an NGO explained, "Teachers often know about it as does the family, but they turn a blind eye. How can you bite the hand that feeds you?"

Two young people were reported to be heading households of orphans. In both instances, the oldest girl child became the family caregiver and left school to take on this role. Both families obtained resources and support from the destitute allowance, NGOs, and churches. The children were fed and clothes and school uniforms were supplied. However, the oldest girl child had foregone any opportunity to finish her education, learn any life skills, or engage in income-generating activities (IGA).

Poverty

One of the most pervasive themes in all aspects of this research was the experience of poverty ($n = 69$). Even families that were considered to be middle class feared that they were quickly becoming poor. A compounding problem was the cost of funerals. Many caregivers had at least one family member die, with some as many as three and four family members dying over a short period of time. Before the onset of AIDS, funerals were elaborate affairs held only on weekends. Now funerals are held daily to accommodate the sheer number of deaths. Also, the elaborate and costly funeral rituals have been curtailed to some extent.

HIV/AIDS predominantly has affected young adults who are usually the family income earners. There were reports of families that were suddenly made destitute through this loss of income. An additional source of poverty and malnutrition was the depletion of family members to farm the arable lands and tend cattle.

Isolation

Caregivers of all ages described a sense of loneliness and isolation ($n = 32$). The sheer burden of work kept them within the house and compound. As one mother explained, "I cannot go to funerals or weddings, not even to church, because I have to be with him all the time, or most of the time. . . . I can't even go to the fields to plough."

Older women often were dislocated from their traditional homes and families. When a son or daughter became ill, some mothers had to leave their homesteads to care for their child ($n = 3$). These women were separated from their usual support group and community. There were also incidents of ill family members returning home to be cared for by their mothers ($n = 8$). They often would bring their children with them,

causing them to be dislocated from school, friends, and other familiar sources of support.

Stigma

The experience of stigma went beyond HIV/AIDS and was experienced also by families living with other chronic or terminal illnesses. In addition, the CHBC programme and NGOs were stigmatised with the label of HIV/AIDS care even though they provided care to families with other illnesses. Key informants voiced considerable concern that this stigma often prevented people from accessing services ($n = 28$). On one occasion, a young family was evicted from their home because it was thought that the girl had HIV/AIDS. In fact, the girl was dying from cancer of the oesophagus. Children were reported to be skipping school because they were ridiculed or scorned for having a family member with HIV/AIDS.

One of the greatest problems encountered in this research was the secrecy surrounding the diagnosis of AIDS. The research team requested more interviews with caregivers of PLHA; however, this request often was denied. It was difficult to ascertain why this was the case. However, some members of the CHBC team voiced discomfort about discussing the diagnosis. One nurse commented:

The HIV status should be known. But as long as we (health care workers) continue to be secretive, then we will role model this to people, families, and communities. We must be more comfortable with the diagnosis and encourage shared confidentiality. People are dying in secrecy. Actions speak louder than words, so we must be seen to be comfortable with disclosure. We can't give an implicit double message, we need to confront the stigma and break it down.

Lack of Knowledge

An important issue pervading much of the data was ignorance and lack of adequate and accurate information, particularly in relation to HIV/AIDS prevention and care ($n = 53$). Health care workers, patients, families, community leaders, traditional doctors, spiritual healers, and government agencies were all identified as needing more information about HIV/AIDS. One of the most identified needs was for counselling education. The health care workers stated that patients and family members required counselling; however, they felt their skills were inadequate to meet this need.

Respondents generally agreed that more education was necessary for the community at large ($n = 38$). They were concerned that young people still were engaging in unprotected sexual intercourse and that the prevention messages were not being taken seriously. Suggestions for community

education included educating the politicians, village elders, chiefs, village council, traditional doctors, and spiritual healers.

Respondents suggested that income-generation education should be easily available and accessible ($n = 53$). Young school drop-outs and other family members should be taught how to grow communal gardens, manage small manufacturing projects, and so on.

The Need for Psychosocial Support

There was an identified need for effective interpersonal communication, psychosocial support, and the promotion of shared confidentiality ($n = 48$). In particular, families identified the need for bereavement counselling and anticipatory guidance. Health care workers also voiced concern that they often felt overwhelmed in their work and had no means of psychological support. Members of the CHBC team also said that they did not know how provide psychosocial support effectively. As a result, they avoided counselling rather than trying to meet the family's need.

The Role of Traditional Medicine

Twenty-six (74%) caregivers or ill family members sought care from spiritual healers and traditional doctors. Explanations for the illness included being bewitched, having bad blood, being possessed by the devil, and breaking important taboos. Remedies included cutting, inducing vomiting, giving enemas, and applying or ingesting herbs. These families also sought Western treatment, and patients often took pharmaceutical products as well as traditional remedies. Families spent as much as 400–600 Pula (\$100–125 U.S.) on these traditional consultations. Some families had been assured of a cure for AIDS. This led family members to have false expectations and be unwilling to accept the medical diagnosis.

CONCLUSION

The results of this study point to some important findings. The burden of care for terminally and chronically ill family members on older women and younger girls is profound. They must assume multiple, often overwhelming, roles. Poverty exacerbates these problems. These caregivers feel isolated, they lack necessary knowledge, and they require effective, easily accessible psychosocial support. In addition, the stigma of HIV/AIDS prevents the availability of an adequate flow of information and care provision for these needy families. Traditional medicine and spiritual healing play important roles in many of the families interviewed; however, the costs of this service can be crippling.

Based on the results of this study, the following recommendations were made: (a) further education related to HIV/AIDS care, prevention, and counselling is required for patients, families, and CHBC team members;

(b) issues of HIV/AIDS stigma and secrecy must be addressed; (c) respite care for caregivers should be considered; (d) young girls should be supported to remain in school; (e) problems associated with poverty must be addressed; (f) joint education sessions should be held between traditional doctors, spiritual healers, and members of the CHBC team; and (g) there should be income-generation activity education for all community members.

In keeping with action research, the results of this study and recommendations were presented verbally and in a written report to the Botswana Ministry of Health. In addition, we reported problems identified during data collection to the CHBC team and, where possible, acted upon them. Recent reports from Botswana indicate that many of these research recommendations now have been acted upon. For example, regular education sessions are now available to patients, family members, members of the CHBC team, and the general community. In addition, a programme is now in place to encourage young girls to remain in school, and poverty reduction is part of the national agenda. The stigma associated with CHBC programmes also is being addressed. In March 2001 Botswana hosted the first regional CHBS conference with 10 Southern African Development Community (SADC) countries with a mandate to strengthen and improve community home-based care. As a result of this conference, the Gaborone Declaration was developed. This declaration highlights eight guiding concepts to reduce stigma and provide effective home-based care in sub-Saharan Africa.

The results and recommendations of this research provide important insight into the experiences of caregivers providing care to family members with HIV/AIDS and other chronic and terminal illnesses at home. In addition, further WHO funded studies are now being conducted in different countries to broaden the scope of these findings. As the results from further studies are compiled, broader strategies for action will be identified. The overall goal of this larger research project is to provide guidance to governments and policymakers on the implementation and sustainability of effective and affordable CHBC in resource-poor settings.

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