Community Home-Based Care: Family Caregiving

Caring for Family Members with HIV/AIDS and Other Chronic Illnesses

The impact on older women and girls

A Botswana Case Study
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EXECUTIVE SUMMARY

This study investigated the experiences and impact of primary caregivers caring for family members living with HIV/AIDS or other chronic illnesses at home in three districts of Botswana. In particular, the focus was on the impact of caregiving by older women and young girls. Botswana has one of the highest rates for HIV/AIDS in the world and hospitals lack the capacity to care for the large volume of HIV/AIDS cases. Therefore, the government initiated a comprehensive community home-based care (CHBC) Programme. In some communities HIV/AIDS patients, and others with chronic illnesses, are now being cared for at home with the assistance of CHBC and family members.

Data Collection:

This study was exploratory and descriptive using qualitative research methods. Two interview guides were generated, one for caregivers and the other for key informants. Thirty-five primary caregivers were interviewed in Setswana (the local language) and the responses translated into English. The second guide (conducted in English) was used to interview 35 respondents including nurses, family welfare educators, social welfare officers, CHBC volunteers, and other stakeholders in CHBC and HIV/AIDS care. A total of seventy interviews were conducted.

Results:

The results provided important insight into the impact of caregiving on older women and young girls. In addition, issues of poverty, isolation, stigma, lack of knowledge, the need for psycho-social support, the role of traditional medicine and issues related to the provision of CHBC were identified.

**Older women** were overwhelmed with the magnitude and multiplicity of tasks they had to perform. They were exhausted, often malnourished, depressed and neglectful of their own health. Although they had been taught to use universal precautions, very few complied with this regimen. When family members became too ill to care for themselves, they often returned to their mothers, bringing with them their own immediate family. Conversely, mothers might be called upon to care for their child at his/her home, leaving their own immediate family and means of psycho-social support behind.

**Young girls** usually played a supportive role to the primary caregiver. This supportive role included performing household tasks and giving personal care to the sick family member(s). Schoolwork often became compromised through exhaustion or the psychological trauma of witnessing the death of loved ones. In addition, many young girls were reported to become prey to older men, and exchanged sex for money and material goods to augment the family income thus increasing their risks for HIV infection and unwanted pregnancy. Sexual and physical abuse within the family was also a concern. Some of these girls became socially isolated and depressed. As a consequence they often dropped out of school with inadequate education or opportunities for future employment.
Respondents identified poverty as a major concern. Often the most active, income-generating members of the family were sick or deceased. Other sources of income were sparse and unreliable. There were reports of people living without food, adequate shelter, warmth and clothing. The high cost of funerals also exacerbated this problem. In addition, families were reported to be too exhausted to engage in income-generating activities. The destitute allowance provided some assistance; however people still went without food and other needed resources.

Social isolation resulted from the high demands of caregiving. In addition, respondents reported that the stigma of HIV/AIDS had caused some caregivers to be cut off from friends and other forms of social interaction. Moreover, the secrecy surrounding AIDS resulted in families not accessing available CHBC resources.

Family caregivers had been given some information about universal precautions; however few of the respondents knew why this was necessary. In addition, many caregivers did not know the diagnosis of the family member. Health and social welfare personnel reported their need for more education on prevention, care and counselling related to HIV/AIDS. It was also reported that more HIV/AIDS education was needed for the general public.

Families caring for someone with HIV/AIDS and other chronic illnesses often accessed both western and traditional forms of medicine. A problem arose when traditional healers claimed a cure for AIDS. In addition, the cost of traditional consultations and treatments further compromised scarce financial resources.

Issues related to CHBC also require attention. In particular the referral component of CHBC requires urgent attention. In addition, there appeared to be bureaucratic bottlenecks whereby resources, services and supplies were either not known about, or were not reaching families in need. There was considerable debate about the role of retired nurses, family welfare educators and social welfare officers. A debate also surrounded whether or not health care workers should be hired specifically for home-based care, or should be able and willing to work in both institutional and home-based care settings. Concerns were also voiced about transportation issues. Finally issues related to respite care, and the value of volunteers and family welfare educators were raised.
RECOMMENDATIONS

Based on the results of this study, the following recommendations were made:

- The referral system between hospital and home requires strengthening.
- Further education related to HIV/AIDS care, prevention and counselling is required for patients, family members and members of the CHBC team.
- The issues of stigma and secrecy surrounding HIV/AIDS must be addressed.
- There is an identified need for more psycho-social support in CHBC.
- Strategies to provide respite care for caregivers should be considered.
- Strategies should be considered to support young girls remaining in school, despite their caregiving roles and responsibilities.
- Issues of poverty must be addressed so that young girls are not tempted or forced to engage in sexual relationships in exchange for money or other material goods.
- There should be joint education sessions between traditional doctors, spiritual healers and members of the CHBC team.
- There should be education sessions on income generation available to all community members.
- Volunteers and other community workers should be honoured for their contribution.
- An expanded role for volunteers should be considered.
- Some of the CHBC government funds should be expanded to support the home-based care initiatives of NGOs.
- There should be better coordination between CHBC and NGOs involved in home-based care.
- Resources and supplies should be distributed equitably, quickly and regularly.
- Ways of linking and coordinating CHBC and TB DOTS activities need to be explored for an optimal use of scarce resources.
- Vehicles for transportation of the CHBC team, patients and families should be available to all villages.
- The principles of individual and community empowerment should underpin all community initiatives, including research and evaluation.
- All research that requires community action should be housed within an action research philosophy.
- This research study should be replicated to ensure consistency and accuracy, and to broaden the scope of these findings. Future studies should be done in different study locations (i.e. different countries).
INTRODUCTION

A 34-year-old woman is caring for her sister and her sister’s child, both of whom have AIDS and TB as a co-infection. She has seven younger sisters and brothers and fifteen children who also live in the home. Twelve of these children belong to her and to her brothers and sisters. In addition, there are three orphans from a deceased brother and sister-in-law who both died of AIDS. The caregiver’s parents died 5 years ago. The caregiver has no formal education, and the family survives on destitute allowance. She makes a small amount of money buying chicken in bulk and selling pieces. She also sells chibuku, a local beer.

The caregiver describes both the sister and her child as “very ill and getting worse”. Both patients have productive coughs, and the sister complains of dizziness and headaches. The infected sister has bouts of crying, after which she says she feels better. The infected baby was hospitalized with a fractured leg three months ago. A letter was sent with the child upon discharge to request the child be given a rich protein supplement and additional milk. However, the family has been told they have to supply these supplements themselves. They say they cannot afford this and as a result, the child eats a light porridge made with water.

The family welfare educators visit the home each day and bring the TB medications for the sister and child. The caregiver has to wash her sister, help her dress and go to the toilet. The baby needs total care. In addition, the caregiver and one of her younger sisters takes care of the home; they collect water from a communal standpipe, collect firewood, cook, shop and do the daily tasks of the household. She explains her responsibilities:

“I take care of all my younger sisters and brothers and I am responsible for the schoolwork. I am the one who is responsible for all the orphans. I make sure they (her sister and child) have enough blankets and I heat the water and bathe them each day. My heart is always painful because of taking care of the baby and the mother. I do feel pains to such a point that my heart beats faster, and I do feel like crying. I don’t know if there is any help I can receive because I am always thinking alone and not understanding what is happening.”

THE STUDY

This study investigated the experiences and perceptions of family caregivers in caring for a person with HIV/AIDS or other chronic illness in community home-based care (CHBC) in Botswana. In particular, this study focused on the experiences and perceptions of women as primary caregivers to ill family members. The specific purposes of this study were to:

• explore and describe the phenomenon of home-based caregiving to family members living with HIV/AIDS and other chronic illnesses by children, youth and elderly women
• raise awareness of home-based family caregiving, particularly in relation to forgone opportunities for a satisfactory quality of life for children, youth and elderly women
• develop sustainable effective strategies/interventions to improve the quality of life for these home-based family caregivers
• develop sustainable effective strategies/interventions to improve the quality of care to persons living at home with HIV/AIDS and other chronic illnesses.

BACKGROUND

The study was conducted in Botswana in the central portion of southern Africa. Botswana is a large, landlocked plateau bordered 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 and English is the official language.

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” (Botswana HIV and AIDS Second Medium Term Plan [MTP 11], 1997-2002, p.5). There is a publicly-funded education and health care system. Primary and secondary education is free with adult literacy at 70% (MTP 11, 1997-2002). Education is in Setswana for the first four years and thereafter in English. Health care is founded on the principles and practices of primary health care (PHC) with 30 hospitals and over 500 clinics and health centres. PHC is mostly free and universally free for children, pregnant women and TB patients. According to the MTP 11, 1997-2002, 85% of the population lives within 15 kilometres of a health facility, while 76% lives within walking distance. Although these distances may seem reasonable, they are a considerable hardship for many people who are ill, or those who have to look after them, who have to walk these distances or travel by donkey cart, although vehicles are becoming more common.

Despite Botswana’s relative affluence in Africa, 47% of the population lives 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:

HIV/AIDS was first recognized in Botswana in 1985. Available epidemiological information indicates that the HIV/AIDS epidemic is now well established. The MTP 11, 1997-2002 reported approximately 13% of the general population infected by HIV with an estimated 23% in the age group 15-49. However, in personal communication with the Manager of the AIDS/STD Unit, it was revealed that more recent figures indicate that 19% of the general population is now infected with HIV. According to the MTP 11 report, there was a cumulative figure of 180 000 persons infected with HIV in 1996, with a projected figure of 332 000 people infected with HIV by the year 2000. This same document reported a cumulative total of 3 650 AIDS cases during the first quarter of 1996. This figure contrasts with a cumulative total of 10 775 cases of HIV related signs and symptoms reported over the same period. The MTP 11 report suggests that these figures are underestimating the extent
of the epidemic. This underestimation is attributed to under recognition, under reporting, delays in reporting, and reluctance to be tested (MTP 11 1997-2002).

The history of the epidemic over the past decade indicates that the people who are the most sexually and economically active are those most affected with HIV. Forty-five percent of the population is between ages 15-49 years, and this age group accounts for 89% of reported HIV cases. Youth aged 15-29 have the highest rate of infection accounting for 56% of the reported cases of HIV in 1996. The Sentinel Surveillance Report (1998) indicated 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 be co-infected with TB. Teenage pregnancies are common with the concomitant risk of STD and HIV infection. According to the 1991 census 19% of all teenaged girls in Botswana are mothers. HIV is also a growing problem among children. The MTP 11 reported that in the first quarter of 1996, a cumulative total of 1 052 cases of HIV signs and symptoms among children aged 0-4 years. In addition, it is projected that by the year 2000 there will be more than 65 000 AIDS orphans (i.e. children under 15 whose mothers have died of AIDS) (Modungwa, Selelo, & Doehlie, 1999).

Slow changes in sexual behaviour remains an area of major concern in Botswana (MTP 11, 1996). A recent research study was conducted in collaboration with the University of Botswana, WHO (Botswana), and the Ministry of Health (Jack, A.D. et al., 1999). The overall objectives of this study were to identify factors that contribute to the spread of HIV/AIDS among students at the university and to recommend appropriate strategies for intervention. The report revealed some alarming findings. While 85% of students reported that they understood the methods of HIV transmission, its consequences and how to prevent contracting the infection, 32% of students used condoms only occasionally or not at all, and 45% continued to engage in multiple-partner relationships. In addition, 4% of students reported that they had had sexual relationships with an HIV-infected person or someone with AIDS. It would appear that knowledge about HIV/AIDS, its transmission and consequences is not enough of an incentive to engage in safe sexual practices.

When the statistics of HIV/AIDS incidence and prevalence are compared with the total population of Botswana, it is clear that the HIV/AIDS epidemic will have profound consequences for the country. In fact it is reported that Botswana has the highest prevalence of HIV in the world (Ngcongco, 1998).

Traditional Beliefs and Customs:

Elderly people in Botswana society are important bearers of tradition, including traditional knowledge about illness and its cause (Ingstad, Bruun, & Tlou, 1997). Ingstad (1997) gathered ethnographic material from folk healers and rural families with disabled family members that provided a picture of Tswana conception of their body and how possible illnesses emerged. The heart is seen as the central organ of the body as well as the centre for feelings, thoughts and emotions. Episodes of illness invariably lead to questions of “why has this happened to me, and why just now”. Tswana healers may identify the origins of disease as witchcraft, ancestor’s anger, break of taboo with pollution and its consequences, or God’s will. While the
first three origins call for specific rituals and/or behavioural measures, “God’s will” is often the diagnosis people resort to when other attempts at treatment have failed. Such a diagnosis calls for acceptance and stoic resignation (Ingstad Bruun & Tlou, 1997, p. 364).

There is no concept of disease transmission through bacterial or viral infections in Tswana folk medicine. Some traditional healers claim that AIDS is a new disease, “like an aeroplane: nobody knows where it comes from and nobody knows where it goes” (Ingstad, Bruun & Tlou, 1997, p.365). However, others claim that AIDS was a Tswana disease caused by pollution as a result of a break in taboo. The only clearly-defined concept of illness transmission is the pollution of blood (meila) through the breaking of sexual taboos. In most cases, pollution is seen as originating in the womb during certain critical periods such as after abortion, an abnormal delivery, or while in confinement after birth. Defined periods of sexual abstinence should be observed followed by purification rituals before sexual intercourse is resumed. A man who violates these taboos may become polluted and consequently sick. His pollution can then be transmitted to subsequent sexual partners, and sometimes to the children through breast milk (Ingstad, Bruun & Tlou, 1997).

In contrast to breaking taboos where pollution is seen to originate in the womb, boswagadi is seen to originate in both sexes. When a couple marries they are thought to share a bodily and spiritual unity in which their blood is intermingled. At the death of a spouse, the surviving partner enters a state in which (s)he may affect the environment in various ways. Thus one year of sexual abstinence beginning and ending with purification rituals performed by a folk healer is prescribed. The widow(er) undergoing one year of abstinence is known as a moswagadi. This person may cause disease to fall upon small children, livestock, or cause crops to fail. A moswagadi must not shake hands, or in any way touch another person, and must be careful looking at people, livestock or a ripening field. If walking outside the compound, the moswagadi must carry a special herb from which the leaves must be thrown on the path ahead. Prohibitions exist against going outside the compound or neighbourhood or participating in places where babies might be encountered. A person who has sex relations with a moswagadi is believed to fall ill almost immediately with boswagadi.

Another Tswana belief is cleansing the blood by having sexual intercourse with a younger person. Informants in a study by Ingstad, Bruun & Tlou (1997) suggested that the practice is often frowned upon since the relationship may cause the young person to catch melia (polluted blood) from the older person and thus become ill. As a consequence, this practice is often performed in secrecy. These study informants claimed that such practices predominantly involve older men seeking younger women to cleanse their blood.

Each type of taboo violation is clearly defined with a Tswana name and in some cases, specific types of symptoms. The process of diagnosis requires investigation into the origins of the condition (usually a type of taboo violation) thereby indicating the necessary purification rituals and herbal remedies (Ingstad, Bruun, & Tlou, 1997).
Traditional folk medicine is usually practised by a spiritual healer or a traditional doctor. These traditional practitioners prescribe various rituals and practices. Providing herbs for ingestion or for topical application are common remedies. If the herbs are to be applied topically, they are often applied with a metal applicator onto skin cuts made by a razor blade. There is considerable debate about the dangers of this practice. Some people believe that the razor blades are used many times without sterilization. Others believe that with the advent of HIV/AIDS, most healers use a new razor blade for each person. It is thought that these remedies are less common in present-day practice. Healing rituals might also include the use of enemas, inducing vomiting, and praying with the use of different coloured candles.

A negative consequence of these traditional beliefs and practices is that boswagadi (illness as a result of sexual contact with a moswagadi) is believed to be curable by folk healers. Thus a person without symptoms who has been tested HIV positive may go to a healer and be told that (s)he is cured, thus feeling free to go on with “risk behaviour” and disregarding the advice of modern health workers (Instad, Bruun, & Tlou, 1997).

Young people with access to education, the media and a broader view of the world have less regard for these traditional taboos and remedies. The elders believe that such disregard “is how AIDS is spread” (Instad, Bruun, & Tlou, 1997, p.366). However, when young people are confronted by a terminal illness such as AIDS, they often revert to traditional healers and remedies.

Population Migration:

A large majority of people in Botswana have three, or sometimes four, homes (Instad, Bruun, Sandberg, & Tlou, 1992). The family homestead is usually in a village, another home is at the “cattle post”, and a third is on the arable “lands”. More wealthy families might also have a fourth home in a town/city. The village homestead is usually the traditional family home. The cattle post is often located some distance from the village, close to a water source and the home on the land is also away from the family homestead. In addition, family members might also work in a town. This movement accounts for “unprecedented human traffic” and makes Botswana one of the most mobile populations in the world (Medium Term Plan (MTP) 11, 1997-2002). Thus there is little differentiation between rural and urban populations with movement of people across considerable distances. This migration further compounds the problems associated with HIV/AIDS transmission. In addition, when a person begins to suffer HIV related illnesses, (s)he often returns to his/her traditional family homestead to be cared for and to ultimately die.

Home-Based Care:

The impact of AIDS on the health sector is great. The MTP 11 for Botswana (1997-2002) reports that 50% of bed occupancy 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) reported that 65% of all hospital beds throughout the country are now occupied by people with HIV/AIDS. This bed occupancy rate creates an overwhelming strain on the health care system. Community home-based
care (CHBC) is seen as a key strategy to sharing this burden of care between hospitals, clinics, health posts, families and the community (Mathebula, 2000).

A Community Home-based Care (CHBC) Programme 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” (National AIDS Control Programme No. 30 [NACP 30, 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 for the following reasons:

(a) The extended family is traditionally the caring unit in Botswana society
(b) Patients prefer to die at home
(c) Inadequacy of institutional health services to fully manage the AIDS epidemic
(d) Sharing the challenge between hospitals, district health services, families and the community
(e) The family is seen as a target for AIDS prevention

As the reality of AIDS deaths are witnessed by family and community members it is anticipated that prevention strategies will become a high priority. In addition, a caring family will reduce the risk of ostracism of people with HIV/AIDS (PWA) (NACP 30, 1996).

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. The National Aids Control Programme Report (NACP 30 Report 1996) outlines the specific objectives of the CHBC Programme:

(a) To ensure optimum level of care for all terminally ill patients in order to avoid the “dumping syndrome”
(b) To avoid unnecessary hospital admission
(c) To provide clinical care in the home, including giving medications
(d) To provide nursing care in a home setting
(e) To provide an on-going counselling service to both PWAs and their families
(f) To refer terminally-ill patients to social, welfare and other appropriate agencies for material support
(g) To establish a functional referral system between hospitals, district health teams, clinics and between districts (NACP 30, p.5)
A baseline study for CHBC was conducted in 1996 (NACP 31). This study contains baseline data that constitutes the pre-test measures within an overall framework of a pre-test/post-test experimental design for evaluating the impact of the CHBC Programme. Various evaluation studies have been conducted in different districts in Botswana (NACP 41, 1998; Ngcongo, 1998). These studies provide important insight into the issues related to CHBC and speak to the overall efficacy of the Programme.

**METHODOLOGY**

This study was exploratory and descriptive using qualitative research methods. The focus of the study was the phenomenon and impact of caregiving by children, youth and elderly women to ill family members at home. Background information on demographics, illness- and treatment-related variables and support resources were collected. The actual work of caregiving including a) direct physical and emotional care, b) management of symptoms and medical regimens, c) the performance of surrogate roles by the caregiver, were explored. Data were also collected on the impact of primary caregiving by children, youth and elderly women. Such data included the effects on the caregiver’s physical, mental, and social health, financial status and on their developmental well-being. Finally, questions were raised to explore strategies that might support family caregivers and the actions that could be undertaken to support these initiatives.

It was hoped that the findings of this study would form a catalyst for action towards reducing the impact on family caregivers, and to enhance their quality of life as they care for a terminally/chronically ill family member in home-based care. As such, this research incorporated the philosophy and processes of action research (McTaggart, 1993). Action research is considered a cyclical process towards effective action, in which empirical decisions on the research topic and on the action embedded in the research topic, and continuous evaluations (of which the outcome redefines, if required, the research topic) are conducted with all partners involved in the process (Wadsworth, 1997).

This cyclical process of action research was actualized within this study by the constant reporting of findings to members of the CHBC team. For example, if a caregiver and her/his family were deemed to be living in extreme poverty, the social worker would be informed and an assessment for destitute allowance would be conducted. Another example was the need for supplies. Where members of the research team ascertained that gloves, mackintoshes, medications or other forms of supplies were needed, a request would be given to the appropriate member of the CHBC team. Sometimes, members of the research team also participated in supply provision. At the end of the study, the principal researcher provided a verbal report on the study 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 terminally/chronically ill family members at home were discussed. It is assumed that action will be taken based on this verbal and written report.
POPULATION AND SAMPLE

The population was a convenience sample (Morse, 1991) of children, youth and elderly women acting as primary caregivers to terminally/chronically ill family members at home. In addition, CHBC volunteers, family welfare educators, nurses, social workers, and members of NGO's involved in CHBC were included in this study. Finally, data were collected from personnel from the Ministry of Health, researchers involved in issues related to CHBC and HIV/AIDS, and consultants involved in CHBC.

It is important to provide details on the membership and working relationships of the CHBC team as an understanding of these roles and relationships in considering the results of this study.

Nurses:

Registered nurses, some with advanced education, are involved in Community Home-Based Care. These nurses may be employed to work exclusively in CHBC, or they may have joint roles between the clinic or health post and the CHBC team. They provide education to family caregivers and other family members, to family welfare educators, and to CHBC volunteers. They also provide direct nursing care to patients, counsel and support the family, and coordinate the care of the CHBC team. The primary health care hospital, health clinic or health post stores the medications and necessary equipment such as gloves, mackintoshes, masks, aprons, and other resources for patient care for CHBC. Nurses provide these necessary resources to the family, the family welfare educators and to the CHBC volunteers.

Family Welfare Educators (FWE):

These workers have 12 weeks of basic health education to equip them to work in collaboration with nurses and other healthcare workers. The role for the FWE was designed to work in the community; however, before the initiation of CHBC, they worked predominantly in the community health facility while visiting people in their homes on a less regular basis. With the advent of CHBC, FWEs have begun to return to the role as it was originally conceived. As a result, they now play a significant role in the coordination and provision of care in home-based family caregiving. The FWEs visit people in their homes, provide necessary supplies and medications, give physical care to the patient, and coordinate and support the work of the CHBC volunteers. In addition, the FWE provides health education, advice and some counselling to the family and patient. The FWE is the liaison person between the CHBC volunteer and the community health post or clinic. This category of health worker has been in existence in Botswana for over 25 years, and fulfils a vital role in primary health care.

Community Home-Based Care Volunteer:

The CHBC volunteers are a new category of community worker that began with the advent of the CHBC Programme. These workers (usually women) voice an interest in CHBC and are then chosen by the community to enrol with the CHBC
team. They receive 3 days of training at the Kgotla (the village meeting house) and then continue their training and supervision while working in the community. Their role is to provide support and care to the patient and family in their own homes. Such work might include bathing, feeding the patient, helping with mobility, preparing food, cleaning the house and compound, collecting wood or water or any tasks that support the work of the primary caregiver and other family members. They often develop close ties with the family and help the family at the time of the illness, and often continue caring for the bereaved family. These volunteers are supported, educated and supervised by the FWE, the social welfare officer and the nurse. Should the family require supplies or medications, this information is supplied to the FWE and action is taken. The government provides CHBC volunteers an honorarium of 100 Pula (approximately $26) a month to support their activities. It should be noted that these volunteers may be poor, and the honorarium may provide some necessary income. The volunteers also receive a CHBC bag for their supplies, a badge, tee shirt and umbrella that has the CHBC logo.

Social Welfare Officers (SWOs):

The CHBC Social Welfare Officers primarily attend to the material and psychosocial needs of caregivers and family members. Families are referred to the SWOs by members of the CHBC team when there are financial, social or legal concerns. If financial concerns are noted, the SWO assesses the family for destitute allowance. Upon determination of need, the family obtains food rations, mattresses, blankets, school uniforms, clothes, coffins or other material requirements that are deemed necessary. In addition, the SWO assists families with legal matters. They help with writing wills and other matters of legal advocacy such as possession rights, acquisition of benefits, etc. The SWO also refers families to other resources and agencies to support their particular needs. The SWO provides psychosocial counselling to clients and family members. These workers also assist in the training of CHBC volunteers and FWEs.

CHBC Team Coordination:

The nurse is the coordinator of the CHBC team. This team consists of nurses, social welfare officers (SWOs), family welfare educators (FEWs), and CHBC volunteers. Doctors are also consulted on particular client issues. Team meetings are held on a regular basis where issues and concerns are raised and solutions sought. These team meetings provide an opportunity for discussion, education, problem-solving and decision-making. Lines of communication are clearly understood and information is shared to improve the care and the quality of life for the patient, the primary caregiver, and other members of the family.
STUDY LOCATIONS

This exploratory study was conducted in three districts within 120 kilometres of Gaborone, the capitol city of Botswana. The districts were Kweneng and Kgatleng and Old Naledi, a suburb of Gaborone. **Kweneng** is within 30 kilometres of Gaborone with a population of approximately 180 000. There are 42 villages that comprise the total area of Kweneng. The study site was the village of Mmopane, consisting of 1 249 people with a catchment area (including arable lands) of 5 000. Mmopane is a rural community with mostly traditional homes. However more contemporary homes are also found in the village. There is considerable poverty in this village with many people living in crowded conditions, collecting water from communal standpipes and without electricity or telephone. Most houses have a pit latrine and there is no indoor plumbing. Very few vehicles are evident in the village. Goats, donkeys and cattle roam around and many family compounds have small vegetable gardens. The goats and cattle are used as a source of food and the donkeys are used for transportation and ploughing. In the larger catchment area there are arable lands where some families tend their farms.

With the advent of HIV/AIDS these arable lands are becoming neglected. Many of the able-bodied family members who traditionally ploughed, seeded and harvested the land are either dead or dying of AIDS. The remaining family members are often poor and unable to pay someone to do this work. The road system is mostly dirt roads and, in more remote areas, these roads are barely visible. A community health post provides health care to Mmopane, with a nurse, a family welfare educator and 8 CHBC volunteers. It is important to note that Mmopane has not as yet been registered on the CHBC Programme resulting in unavailability of many resources that are available to the registered CHBC Programme villages. They are in the process of undertaking this registration. The greatest problems identified by this village are lack of transportation, communication (telephone), and the poverty of the people. It is hoped with CHBC registration, some of the more urgent needs for supplies and services will be forthcoming.

**Kgatleng** is a district between 70-130 kilometres from Gaborone. The research team visited two villages, Mochudi and Artesia. Mochudi is the capitol village of Kgatleng district with a population of 40-50 000, while Artesia (60 kilometres north) is a small, remote village. Mochudi has a primary health care hospital and a large health clinic providing a comprehensive array of health services. The CHBC nurse Coordinator and the social welfare officer for the Kgatleng district are stationed in this central location. Mochudi appears to be a comparatively prosperous community with shops, legal facilities, the district council offices, banks, police headquarters, and other administrative and support facilities available to the population. The roads are predominantly paved and most houses are built of brick or concrete construction.

In contrast, Artesia is a small, rural village consisting mostly of traditional circular homes with thatched roofs and expanses of arable land. The recent torrential rains had damaged many of the outer earthen walls of these houses. Most houses are without electricity, and water is collected from a communal standpipe, although some homes have their own water supply within the compound. Fires are the most common
form of heat, light and cooking, with paraffin lamps used for additional light. It should be noted that some houses also have television, although these are an exception. Some houses have pit latrines but many household use the surrounding bush. The nurses, family welfare educators, and CHBC volunteers are based at the health post in Artesia where CHBC coordination takes place.

Old Naledi is a poor suburb of Gaborone with a population of 20-30 000. There is a maternity hospital, and a large health clinic. Most of the houses are of concrete or brick construction, however, some houses have the traditional earthen construction. The water supply is from standpipes, either within each compound, or within a short walking distance. There are food stalls, some shops, a tuck shop (small food stand that sells cooked food items and other food supplies) and other commercial activities. Old Naledi is close to a paved road on the outskirts of Gaborone, however, some of the roads within this suburb are of dirt construction.

The health clinic and maternity hospital address most of the health care needs of the community; the large referral hospital in Gaborone is within a short driving distance. There appears to be adequate transportation within the community and to adjacent health resources. The CHBC is coordinated from the health clinic and the CHBC administrative offices which are located in Gaborone. A striking difference between Old Naledi and the other study sites is the transient nature of the population. As with any poor suburb of a large city, Old Naledi has many social problems. Alcoholism, crime, and family disintegration are common. When people who are disenfranchised by their families become ill (mostly from AIDS) they often rent a room in a person’s house, and the house owner and/or CHBC team assume the caregiving activities. It is also known that some people are left in these rented rooms alone and uncared for.

The government is encouraging people who are terminally ill to return to their traditional homes. This occurs in some instances, but in others, the mother is called from her village to care for the ill person and other family members. This often means that the mother is placed into a completely foreign environment with none of the usual support mechanisms available to her as at home. Such dislocation is very stressful as city life is unfamiliar, and the mother often leaves her own family behind in her village.

DATA COLLECTION

Data were collected by the use of two questionnaires. The first questionnaire focused on the experiences and perceptions of caregivers in caring for ill family members at home (see Appendix A). 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. A total of thirty-five caregiver interviews were conducted in this manner.

The second form of data collection involved open-ended interviews with key informants (see Appendix B). Key informants included members of NGO’s, CHBC volunteers, family welfare educators, nurses, social work officers, personnel from the Ministry of Health, researchers and consultants involved in issues related to
HIV/AIDS and CHBC. These interviews were conducted predominantly in English, however, some interviews with CHBC volunteers were conducted in Setswana and translated into English. The interviews were either tape-recorded and transcribed or notes were taken directly onto the questionnaire. Thirty-five key informant interviews were conducted. Table 1 provides an overview of the composition of the key informants.

<table>
<thead>
<tr>
<th>Key Informant</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-governmental organization personnel</td>
<td>5</td>
</tr>
<tr>
<td>CHBC volunteers</td>
<td>6</td>
</tr>
<tr>
<td>Family Welfare Educators</td>
<td>9</td>
</tr>
<tr>
<td>Nurses</td>
<td>7</td>
</tr>
<tr>
<td>Social Welfare Officers</td>
<td>1</td>
</tr>
<tr>
<td>Personnel from the Ministry of Health</td>
<td>3</td>
</tr>
<tr>
<td>University lecturers/researchers</td>
<td>3</td>
</tr>
<tr>
<td>CHBC consultants</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>35</strong></td>
</tr>
</tbody>
</table>

Access to Participants:

The study locations were decided upon with the collaboration of the University of Botswana researchers and personnel from the Ministry of Health. Before visiting the sites, permission was sought to conduct the study from the district CHBC team. Once this permission was granted, the research team met with members of the CHBC team, including nurses, social welfare officers, family welfare educators, CHBC volunteers, and in one instance, a local physician. The research team explained the focus of the study in both English and Setswana. This was followed by general discussion and clarification of the study’s purposes and goals. At this meeting, family caregivers were identified and a plan for visiting the research sites was made. The following day, the nurse, family welfare educators, CHBC volunteers and social welfare officers accompanied the research team to the study site. At the study site, a research team member was allocated to certain family welfare educators, nurses and/or CHBC volunteers. These teams then went to visit the identified caregivers where introductions were made and the purposes of the study explained. It was stressed to the caregivers that refusal to participate in the study would in no way jeopardize the care, support and health care the caregiver and family received from the CHBC team or other health care workers. Permission was then sought to interview the caregiver. Once this permission was granted, members of the CHBC team left the home and the researcher and the caregiver undertook the interview. It is interesting to note that no caregiver refused to be interviewed. The research team thought that perhaps two reasons accounted for this. First, the CHBC team had carefully identified the caregivers, and they had been prepared for the visit. Second, although no assurances were made to the participants, it was thought that the caregivers were hopeful that by describing their experiences of family caregiving, improvements would be made to the services they received. In keeping with action research, small improvements were made whenever possible. These actions are described throughout this document. In addition it is hoped that the results of this
manuscript will further improve the support and care of patients, families and primary caregivers

The key informants were identified by the University of Botswana researchers, personnel from the Ministry of Health, members of the CHBC team, and through recommendations from various people associated with CHBC and HIV/AIDS. These people were approached directly by the principal researcher or members of the research team. Once the focus of the study was explained and permission granted, the interviews were then recorded either by the use of a tape recorder or through note-taking. Again, no key informant refused to be interviewed.

Research Integrity:

The principal researcher and author of this report is not from Botswana, and cannot speak Setswana. For this reason, the research team was very sensitive to issues of translation, observation and knowledge of local customs and practices. For example, in interviewing family caregivers, the principal researcher visited all the study sites and also visited many of the homes of the caregivers and family members. Once introductions were made, the principal researcher left the compound and a member of the research team conducted the interview. At lunch, and at the end of each day, the research team would meet to discuss issues related to data collection and contextual understanding. It was found that certain words in the questionnaire were ambiguous in Setswana. For instance, the word for “crisis” did not have the same meaning, and the difference between “religion” and “spirituality” were not easily understood. As a result, agreements were made as to the most appropriate Setswana word to convey a particular meaning. In addition, as data were collected it was found that some questions needed further elaboration. The questions related to “health seeking behaviours” drew responses about traditional doctors and spiritual healers. It was deemed necessary by the research team to add a second question to understand more fully what traditional health practices were undertaken. Discussions also surrounded the living conditions and traditional customs and practices of the families in the study. In this way it was considered important that the principal researcher have as broad an understanding as possible about the lives, practices and conditions of the study participants.

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

In summary, a total of 70 interviews (35 caregivers, and 35 key informants) were conducted for this study. In keeping with qualitative research methods, the purpose of determining sample size was to reach redundancy or saturation of the data. It is believed that such saturation was achieved in this study.
DATA ANALYSIS

Data analysis was conducted 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. The key informant interviews were analyzed using 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 meta-themes 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. The actual work of caregiving will then be highlighted. Finally, the impact of providing care to a family member with HIV/AIDS or other chronic illness at home will be presented.

Demographic Variables of Family and Primary Caregivers:

There were 35 primary caregivers (3 males and 32 females) interviewed for this study. The demographic data for age, marital status, years of education, socio-economic and employment status are summarized in Table 2.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-26 years</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>27-55</td>
<td>13</td>
<td>37%</td>
</tr>
<tr>
<td>56+</td>
<td>19</td>
<td>54%</td>
</tr>
<tr>
<td>unknown</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Marital Status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single (unmarried, divorced, widowed)</td>
<td>25</td>
<td>72%</td>
</tr>
<tr>
<td>Married</td>
<td>10</td>
<td>28%</td>
</tr>
<tr>
<td>Female headed households</td>
<td>23</td>
<td>66%</td>
</tr>
<tr>
<td>Male headed households</td>
<td>12</td>
<td>34%</td>
</tr>
<tr>
<td>Years of Education:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2 years</td>
<td>20</td>
<td>57%</td>
</tr>
<tr>
<td>3-6</td>
<td>8</td>
<td>23%</td>
</tr>
<tr>
<td>7-9</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>10-12</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>unknown</td>
<td>5</td>
<td>14%</td>
</tr>
<tr>
<td>Socio-economic status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>20</td>
<td>57%</td>
</tr>
<tr>
<td>Middle class</td>
<td>15</td>
<td>43%</td>
</tr>
<tr>
<td>Wealthy</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Employment status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>4</td>
<td>12%</td>
</tr>
<tr>
<td>Unemployed home maker</td>
<td>31</td>
<td>88%</td>
</tr>
</tbody>
</table>

Figures in Table 2 indicate that the vast majority of primary caregivers were in the middle- to older-age brackets. Their marital status was predominantly single with 66% of the households headed by women. The reason that some women were married and headed the household is that husbands migrated to other parts of Botswana and other African countries to work. The vast majority of the caregivers had little or no education with the socio-economic status of the family being predominantly low. Only four caregivers had employment outside the home and two of these caregivers had piece jobs (temporary employment).
Socio-economic status was determined by family income and from the living conditions of family members. The homes that were considered middle class would have more rooms to house the family with separate sleeping rooms. They would have a standpipe for water within the compound and a pit latrine. Most of these compounds had vegetable gardens and fruit trees, with goats, chickens, donkeys and other animals surrounding the home. In many of the middle-class homes cooking was still done by an open fire within the compound, but some had a cooking stove inside. In addition, some of the middle-class homes had electricity and five had television sets. By contrast, in the poorer homes there were fewer rooms and family members were crowded with no separation for living and sleeping. The standpipe was usually a distance from the house. There might be a pit latrine, or the family might use the bush. The houses were of poorer construction, generally mud with thatched roofs. Botswana just had suffered torrential rains, and these houses were in a state of disrepair. There was less evidence of gardens, fruit trees or animals near the poorer homes.

Family income was more difficult to ascertain. Only four of the primary family caregivers had salaried work, and two of these had temporary work. Although ten of the caregivers were married, often their husbands had retired or did not contribute to the household. Only two of the female caregivers received income from their husband’s employment. The elderly in Botswana receive 110 Pula per month (approximately $26). This pension was often the only source of income in the family. If a family was assessed as destitute, rations and other material goods could be supplied by 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 a reliable source. In addition to a lack of income, other sources of family income were dwindling. When the family was well, the men would tend the arable lands and the cattle. Produce from this farming would contribute to the family income. With the advent of HIV/AIDS, many of the able-bodied family members were either too sick to continue this work or had already died. Many caregivers commented that caring for an ill family member at home was a considerable drain on already scarce resources, and even those who were considered middle class were quickly becoming poor.

Mothers (12) were the most common primary caregivers, followed by grandmothers (7), sisters (2), daughters (4). There was also one husband, one brother, one uncle and one daughter-in-law acting as a primary caregivers.

When considering the difference between the three male carers and the others, it seems that the only real difference was that the men were caring for family members with a chronic illness, and none of them was caring for someone with HIV/AIDS. This might reflect the fact that it is usually men who are infected first. The numbers, however, are too small to draw any conclusions.

Illness, Treatment and Caregiving Variables:

Of the 35 caregivers interviewed, 15 were caring for one or more family member with HIV/AIDS and 20 were caring for a family member with other chronic illness. It is interesting to note that all the CHBC teams stated that the majority of
their patients had HIV/AIDS, yet it was difficult to interview these caregivers. No firm numbers were given to the research team regarding the number of HIV/AIDS patients. It appeared that issues of confidentiality precluded the researchers from interviewing certain caregivers. In contrast, Hospice, an NGO in Gaborone, was able to give the research team exact numbers of HIV/AIDS patients (88) and patients with other chronic illness (12). All the caregivers interviewed from Hospice were caring for PWA’s. Table 3 provides an overview of these illness related variables.

<table>
<thead>
<tr>
<th>Illness</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS</td>
<td>15</td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td>8</td>
</tr>
<tr>
<td>Cancer</td>
<td>4</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>2</td>
</tr>
<tr>
<td>Severe Arthritis</td>
<td>2</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>2</td>
</tr>
<tr>
<td>Head Injury</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
</tr>
</tbody>
</table>

Table 3: Illness-Related Variables (n=35)

There seem to be some qualitative differences in the experience of people caring for someone with HIV/AIDS vs those caring for people with other chronic diseases. The latter had regularly been caring for their family member for quite some time, and would like to care for them into the foreseeable future. There was, therefore, a long-term commitment to care and caregivers were often exhausted. In contrast, the caregivers of AIDS patients were caring for a shorter period of time. The family member usually did not return “home” or call on their family member to help until they became very ill. Also, their care needs might be intermittent with some periods of time when patients were quite well again. However, although the time period was shorter (because of death) and the duration of caring was intermittent (due to the unpredictability of the disease), the psychological and financial impact was enormous. The caregiver was often caring for a child or grandchild and the “natural order” of deaths was disturbed. That is, the younger members of the family were dying before the older members. Family members who were dying were often the main income providers and so the impact on family income was profound. Finally, there was the added impact of caring for more than one family member dying of AIDS and the subsequent responsibility and care for the orphans.

When asked what they thought caused the patient’s illness, very few caregivers had any knowledge. Only four caregivers believed that a virus caused HIV/AIDS. Others said they did not know. One caregiver said that the church believed her daughter had demons while another thought it was witchcraft. She believed that her daughter’s panties were stolen and when found, were worn again without washing.

Although registered in CHBC, two caregivers refused to seek help and advice from the health clinic or the CHBC team. They remained isolated in their care. The other caregivers actively sought help, advice and support for their caregiving role. On the whole, the caregivers were satisfied with the care, support and advice they received from the CHBC team. However, supplies, applications for destitute
allowance and medications were often very slow to materialize.

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

When asked to rate their quality of life, 20 caregivers (57%) stated it was poor, 9 (26%) stated it was neither good nor bad, and 6 (17%) rated their quality of life to be good. These same caregivers were asked to rate the impact the role of caregiving had on them and 26 (74%) stated the impact was high, while 4 reported caregiving to have had a medium impact on their lives, and 5 considered the impact to be low. Interestingly, although the vast majority of 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. These caregivers state that although the impact of caregiving was high, they were satisfied to be carrying out this role. Such comments as “she is my daughter, I want to care for her all that I can” speak to the sense of commitment and responsibility family members felt about their caregiving role. Two examples are provided to exemplify the role of caregivers.

Example One:

A grandmother is caring for a 10-year-old child and her mother, both living with HIV/AIDS. This diagnosis is clouded in secrecy. It was thought that the child contracted the virus through sexual abuse, however, this could not be confirmed. The child has oral and oesophageal thrush and TB and her mouth is bleeding. She is very emaciated and complains of painful swollen legs. Her mother is also wasting and lethargic. Two other family members have already died of AIDS. The grandmother (age 55) provides physical care to the granddaughter such as bathing, feeding, and helping her to the toilet. The mother is able to care for herself at this time. The caregiver also collects wood, cooks, and does all the household tasks. In addition, she takes care of two of her brother’s orphaned children. She considers the impact of caregiving as very high and her quality of life to be poor. She admits to feeling depressed. This caregiver has received instruction on caring for her family members and has been provided with adequate supplies and medications from the CHBC team. A CHBC volunteer visits each day and helps the grandmother with her daily tasks.

Example Two:

A daughter (age 68) is caring for her mother (age 84) who had a stroke with paralysis, spasticity and muscle wasting. She bathes and feeds her mother and changes her nappies. She does all of the household tasks and maintains the house and compound as best she can although, even with her efforts, the house smells of urine.
In addition to caring for her mother, there are three orphaned children in the family, and two additional children under the age of 5 years. The oldest orphan girl helps with the family tasks as she has dropped out of school due to teenage pregnancy. The family had to stop farming and every other form of income generation to take care of the family members. The caregiver used to be actively involved in the community but she has now had to stop all community activities. She rarely visits friends or has people visit her. They often run out of food and other supplies and rely on the old-age pension as the only source of income except for the destitute allowance. This caregiver admits to feeling depressed with a diminished quality of life. Three months prior to this interview, the CHBC team began to visit this family. They now receive nappies, mackintoshes, mattresses and other supplies. The CHBC volunteers visit once a week which the caregiver considers to be adequate.

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 on children, youth and elderly women as primary caregivers. First, the impact on elderly caregivers will be presented. This will be followed by the impact on young people involved in caregiving. Finally general issues related to caregiving will be presented. These issues include: (a) poverty, (b) isolation, (c) stigma, (d) lack of knowledge, (e) multiple roles, (f) the need for psychosocial support, (g) the role of traditional medicine, and (h) issues related to the provision of CHBC.

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)

At the onset of this research, the elderly were considered to be women over 60 years of age. This research has revised the definition of this age group. Many of the women caregivers were 50 years old or older and caring for children, grandchildren, great grandchildren, and on many occasions, other family members as well. Because families tend to have children earlier in Botswana, the role of grandmother and great grandmother comes earlier to these women. Therefore, the experiences of women 50 years old and older were included in this group.

The overriding experience for older women is one of exhaustion. As one nurse explained, "they need to be the ones in bed". Very often the caregiver was caring for more than one sick family member. In addition, many caregivers were caring for orphans from the extended family as well as caring for their immediate family members. These elderly caregivers were often the ones 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.

An example of the complexity and arduous nature of these caregiver's lives can be described in the process of preparing a meal. Wood is increasingly hard to find and caregivers often have to walk several kilometres to find the nearest available
wood. Matches then have to be found and a fire started. In addition, sorghum or other meal requires pounding and water for cooking has to be collected. Finally vegetables have to be harvested. These tasks are often repeated twice a day.

The actual caregiving activities were also reported to be very taxing. Caregivers described caring for family members with incontinence, diarrhoea, vomiting, confusion, and suffering pain. The sick people often had bed sores and required turning, changes of bed linen and nappies, feeding, bathing and administration of medications. As one participant noted: "tiredness has many faces". Caregivers also talked of feeling overwhelmed with all the responsibilities that had been thrust upon them. 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".

Many caregivers were themselves ill. They complained of hypertension, TB, arthritis and diabetes. It was reported that the primary caregivers often lived only a few days or weeks after the death of the sick family members. Although the caregivers were advised by the family welfare educators and nurses about the use of universal precautions while caring for their ill family member, very few caregivers heeded this advice. 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".

Therefore, many of the caregivers engaged in risk behaviours in their care. One family welfare educator noted that the supply of gloves often remained the same. However, whenever she visited the families, the caregiver would use gloves in her presence.

Another concern noted by the nurses, CHBC volunteers and family welfare educators was depression and personal neglect of the caregivers. Malnourishment was a common concern. These older women would feed the family and the sick person first, and often there was no food left for them. The key informants also noted that the caregivers often did not bathe, wore dirty clothes, and seldom slept. Often the most sleep a caregiver would get was when the sick family member was resting. One caregiver explained her dilemma,

"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".

The impact of AIDS has had profound effects on family life. Children often return to the family homestead to be cared for by their mothers when they get ill. They bring with them their own immediate family that usually consists of children and, possibly, grandchildren. Therefore, the mother not only has her sick child to care for, but the child's family as well. On other occasions, the mother might be called upon to leave her own family and travel to the city to care for her child. This
might be the first time the mother has left her village, and the experiences of city life are often overwhelming. They have not experienced crime, alcoholism, and other social problems before, and they may also suffer a sense of separation from their normal support mechanisms. As a result these older women often feel isolated and overwhelmed with caring for their ill child while trying to negotiate city life.

As a result of AIDS the extended family is also seen to be disintegrating. Many of the traditional roles that were undertaken by different family members are no longer possible. Men used to tend the cattle, plough the land, 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. This often means that the older woman takes on the caregiving role for the extended family including orphan care. Family income generation is compromised, while the need for family income increases. As one mother explained.

"We are suffering because of lack of income. I need money to support my family because I can't go to work. I am always in the same place. I need rations."

Some caregivers found religion to be a comfort. They explained that their belief in God had been strengthened as they tried to understand the impact of the illness. As 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 that they had no time to go to church and they no longer worship at home. They felt abandoned by their church and the support of the congregation.

Only two caregivers acknowledged that they engaged in risk behaviours as a result of caregiving. One woman explained,

"If I think about all these problems I have to go and buy beer and drink here. The difference is when I sleep after drinking, I don't have to think too much. And I also know that it is not healthy."

Overall, the burden of care for elderly women was profound. They felt overwhelmed by the sheer volume of tasks they were required to perform. In addition, they neglected their own health, engaged in risk behaviours and often felt depressed. These caregivers considered caregiving to be their duty and responsibility even when it compromised their own health. Many caregivers turned to religion for solace and understanding.

**Youth and Children as Caregivers:**

It is important to note that only two young people were interviewed about their experiences as primary caregivers. Many young people played a supportive role to
the primary caregivers, and were not home at the time of the interviews; they were either at school or at work. However, the role of young people as caregivers was well described by key informants—in particular, nurses, family welfare educators, CHBC volunteers, and members of NGO's. In most cases young girls played a vital role in supporting the primary caregiver. As 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."

These girl children might attend school, although some did not. It was reported that, in most instances, their school work suffered. Girls were expected to rush home from school at lunch and after school to help with the household chores and caring for the sick family members. Very often, the girls did not have time for homework or were too tired to do it. In addition, it was reported that they often had difficulty concentrating on school work because they were exhausted and malnourished. As a consequence, even bright children became poor students and many chose to leave school. It was noted that within the family there was very little encouragement for the girl to continue her schooling if her help was needed at home.

Many respondents described the psychological trauma and depression experienced by young girls as they watched their parents and other family members dying from AIDS. They described young girls living with no hope, a sense of despair and "living in constant fear of losing a loved one". These key informants explained that young girls often contemplated, attempted, or committed suicide.

Young girls were also reported to be socially isolated, with no time to play or engage in other age-appropriate activities. Their lives evolved around school and caring for the family. They were often awakened at night to help in personal care of a sick family member. Other girls were reported to skip school as they feared leaving an ill parent alone. As these girls dropped out of school, their opportunities for future employment were naturally compromised. They had very few life skills, and were not in a position to attend workshops, and other educational opportunities to enhance their employability. One caregiver explained a dilemma she saw for the young girl in her family.

"The girl can't even seek employment because she has to be here every time, and take care of the patient, like fetching water, taking her to the toilet, because I can't do that."

Key informants also reported problems of physical and sexual abuse of young girls. These young children were often abused (either sexually or physically) by a family member. Three children in the study were thought to have contracted HIV as a result of familial sexual abuse. Abuse was rarely discussed but the key informant noted it as a concern and a suspicion as they visited various homes. Only on one occasion was physical abuse acknowledged. A 14-year-old girl was dying of AIDS and was reported to be beaten by her father and older brother. In addition, food supplied by an NGO was taken from the child to feed the father and brother. As a result, the mother hid the food with a neighbour and the child was fed when the male
family members were away from home. This young girl also suffered psychological abuse from her father. On one occasion, the father began the rituals for the dead over the child while she watched his behaviour. She was psychologically traumatized for some time following this incident, and a counsellor from a local NGO helped the child address and resolve some of the feelings associated with this abuse.

Issues of poverty had considerable ramifications for young girls. The key informants reported that one way young girls sought to alleviate this poverty was to sell their bodies for sex to wealthy older men. There were many examples cited of young girls engaging in sex for money or other material goods. Often family members were aware of this activity, but were so grateful for the small material advantages that resulted from this activity that they chose to ignore the behaviour. As one 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?"

In another example, the family encouraged their daughter to have sexual relations with a policeman. The money acquired by this means helped the family members financially, however, the young girl eventually contracted HIV.

The key informants also noted that young girls often engaged in risk behaviours such as alcoholism and recreational sex. As a result, there were reports of high incidence of teenage pregnancies. These respondents were concerned that young girls were not educated about sexuality and the dangers of unprotected sex. One nurse explained,

"We Africans don’t talk about sexuality. We don’t know enough about the transmission of illnesses, and some of the girls think you can catch AIDS through the air."

As the extended family system disintegrated, many of the social and cultural norms that used to dictate the behaviour of young girls were becoming eroded. It was reported that there were fewer social controls and young girls were living and behaving in ways that would not have occurred in the past. For example, there were some reports of young girls who refused to help with any form of family caregiving. They would leave the family and go to discos or to other forms of enjoyment and recreation. As one family welfare educator explained, "they are out of control, with no family discipline, and no one left to provide guidance and support".

Two young people were reported to be heading households of orphans. In both instances, the oldest girl child became the family caregiver to her siblings. These young girls left school to take on this role. Both families obtained resources from the destitute allowance, NGOs and churches. The children were clothed and fed and school uniforms were supplied. However, the girl child had foregone all opportunity to finish her education, or to learn any life skills or engage in income-generating activities.
Only two young women who acted as primary caregivers were interviewed for this study. One 21-year-old girl was caring for an elderly grandmother and had two children of her own. She did not have the support from the fathers of her children, and she described a sense of isolation, loneliness and lost opportunities as a result of her caregiving role. She stated, "I feel stuck at home, I can't get out, and I don't have friends. I wish I could go back to school." When questioned as to why she did not return to school, she explained that this was impossible since she had to care for her grandmother and her own two children.

The other caregiver interviewed was a young woman who cared for her sister with cancer. She voiced pleasure in being able to take on this caregiving role. She was married and had a small child, and she viewed the care of her sister as an important duty she could perform.

The research team made every effort to interview other young girls for this study. However, it appeared that the young girls were not home during the time of the interviews. In future research, every effort should be made to include more young girls in the research to learn more about their experiences first hand, rather than through the eyes of other key informants.

Poverty:

One of the most pervasive themes that went through all aspects of this research was the experience of poverty felt by almost all the respondents. Even the families that were considered to be middle class feared that they were quickly becoming poor. Botswana has a health and social welfare system that supports families in financial hardship. The respondents in this study, however, voiced considerable concern about poverty and the ramifications of being poor.

A compounding problem was the cost of funerals. Many of the family caregivers interviewed had 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 used to be elaborate affairs that were held only at the weekend. Now funerals are held every day in some areas to accommodate the sheer number of deaths. Also, the elaborate and costly funeral rituals have been curtailed to some extent. Nevertheless, the cost of funerals was still considered to be very high. Many families still opt for expensive coffins and hire a private undertaker to care for the body because the hospital undertakers can only keep the body for 3 days. An important tradition in Botswana is the slaughtering of an ox or a cow to bid farewell to the departed and there is usually a lot of food at funerals. This custom places an additional burden on families who are already experiencing poverty and debt.

Of the 35 caregivers interviewed for this study, 8 respondents stated that they had no source of income and relied solely on the destitute allowance. They stated that this destitute allowance was not enough to provide nutritious food for the family and that the rations usually ran out before the next allowance was due.

The older family caregivers received a pension of 110 Pula per month (approximately $25). They stated that this was inadequate to supply food, clothing
and other material resources to all the members of the extended family who now required assistance. These older caregivers had been forced to apply for the destitute allowance, although some of them felt embarrassed to ask for assistance. In one instance, the extended family had been too embarrassed to ask for financial help and had prevented the older caregivers from applying for the destitute allowance even though it was desperately needed.

The destitute allowance provides rations for food, and other material goods such as blankets, mattresses, and school uniforms. Assistance can also be given with the cost of funerals. Some caregivers reported that the destitute allowance was not always easy to access. A social welfare officer had to visit the family and fill in a form to assess family need. This form was then sent to a government agency where the allowance was processed and rations finally supplied. There were several problems with this system. For example, in one village there was no social welfare officer and there was no transportation to allow the district social welfare officer to visit these families. A member of the research team finally drove the social welfare officer around to allow for assessment of need to be made. Also, once the assessment for destitute allowance was made, considerable time elapsed before the rations were forthcoming. In one instance, the family waited over three months. During that time, the family had very little money, food or other material resources.

Twenty three of the caregivers (66%) received some form of assistance from members of the extended family. Usually, this assistance was in the form of food, although some family members also provided money. This source of income or supplies could not be guaranteed. As a result, there were times when the family ran out of food and other material goods. In addition, because of the sheer burden of caregiving, family members were not able to engage in income-generating activities. It was apparent that many family members were ignorant of how to help augment the family income.

It should be noted that four caregivers were employed. However, two had temporary employment, which could cease at any time. The other two respondents had full-time jobs that they were desperately trying to maintain.

HIV/AIDS has predominantly affected young adults who are usually the income earners within the family. These young people have been forced to leave their jobs due to illness and eventual death. There were reports of families that were suddenly made destitute through this loss of income. An additional source of poverty was the depletion in the number of family members who could farm the arable lands and tend the cattle. These activities had been a traditional form of income and support for the family. However, this income generation had already ceased for many families or was at risk of ceasing in the near future.

The result of poverty was that families often went hungry. Caregivers and key informants all provided examples of families who went without food, or ate a watered-down form of porridge as their only sustenance. On several occasions it was noted that family welfare educators and CHBC volunteers, many of whom were also poor, provided food or other resources to these very needy families.
Isolation:

Caregivers of all ages described a sense of loneliness and isolation. The sheer burden of work kept them within the house and compound with very little opportunity to visit other people and places. 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."

And another caregiver noted,

"I don't have friends any more. I had a lot of friends but they have fallen off. When you are in the deep, they run away from you."

Older women were often dislocated from their traditional homes and families. When a son or daughter became ill, some mothers reported leaving their homesteads to care for the sick family member. These women were separated from their usual support group and community. In two instances, these mothers had also left their husbands and other family members at home. These women were placed in new, unfamiliar and sometimes alien environments with none of the usual mechanisms for social support available to them.

There were also incidents of ill family members returning home to be cared for by their mothers. Often they would bring their own children with them. Again, these family members described social isolation as they left their usual sources of friendship and support. Children were dislocated from school and had to settle into a different environment and develop a new circle of friends. On one occasion, a daughter with AIDS ran away from her mother's home and went back to Gaborone to visit her boyfriend. The mother spent three days searching for her daughter and eventually brought her back to the homestead. The daughter became very ill upon her return.

Young girls were also reported to experience isolation. The girls who attended school were reported to rush home at lunch and after school to help the caregiver. They did not play with other children or engage in other age-appropriate activities. Young girls were also reported to be ashamed of having family members with AIDS and they hid this fact from their peers. They withdrew from friends, peers and adults in an attempt to hide the family problems. Members of NGOs explained that they were attempting to support these young girls and make a place for them to go after school to do their homework or just relax. However, few girls took advantage of this resource due to the pressures of home commitments.

On two occasions, people living with HIV/AIDS were reported to be isolated from their families. They were abandoned by their families and lived in rented rooms. On one occasion, the land-lady looked after the man and on another occasion, the man's girlfriend took over his care.
Stigma:

Stigma is still one of the greatest barriers to effective care for people living with HIV/AIDS. In this study, the experience of stigma went beyond issues of HIV/AIDS, and was also experienced by people and families living with other chronic illnesses. CHBC and NGOs that organize and provide care for people at home have been stigmatized with the label of HIV/AIDS care. In addition, orphan care is considered to be solely for orphans of PWAs, although this is far from the case. Key informants voiced considerable concern that this stigma often prevented people from accessing services. Families were reported to refuse care because they did not want their neighbours to see an NGO or a CHBC team member enter their homes. In addition, some families who had been receiving care suddenly refused such care because a neighbour or other community member had noted the assistance of the CHBC team or other NGO. These key informants discussed ways to broaden the perceptions of people accessing home or orphan care but to date, no strategies appeared to be successful. For example, a hospice NGO stopped putting their name on the cars that counsellors or nurses took to visit families. However, even without these labels, neighbours and other community members recognized the car and made assumptions about the cause of the illness. 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. There was also the example of the child who was physically abused by her father and brother because “she had brought shame to the family”. In addition, it was reported that people who rented rooms were often evicted once it was known that the person had AIDS. These people either returned to their parents or they sought other rental accommodation while trying to hide their illness. One family was reported to have locked the PWA in the house all day while they went to work. This was a wealthy family, however, they had no caregiver remain with the PWA. An NGO visited this home and managed to enter by an open window. They found the PWA in a soiled bed in a room with no ventilation, water or food. Another family was reported to have hired a woman to care for the PWA without informing the hired caregiver of the patient’s diagnosis. This woman was caring for the PWA without any education about HIV/AIDS care or the use of universal precautions.

One caregiver said that she and her family had kept the diagnosis of HIV/AIDS a secret because they feared that the members of the CHBC team would gossip with their neighbours. However, when the diagnosis became known through a severe bout of thrush, the family realized that the CHBC team did not share this knowledge with others. As a result, shared confidentiality was established and the subsequent care of the patient was reported to have improved.

One of the greatest problems encountered in this research was the secrecy surrounding the diagnosis of AIDS. Only four caregivers (out of a total of 15 PWAs) knew the diagnosis, and how HIV/AIDS was transmitted. The research team would ask the CHBC team if they could interview caregivers of people living with HIV/AIDS. On many occasions, this request was denied (by the CHBC team)
because of the secrecy surrounding the diagnosis. On other occasions, the interview took place without the interviewer or caregiver discussing the diagnosis. The interviewer would ask the diagnosis of the patient, and the caregiver would reply that she did not know. However, the research team member was cognizant of the diagnosis, either from discussions with the CHBC team or through observation of classic opportunistic infections. In many instances, the diagnosis that the caregiver had been given was TB. This was often the case since the patients often had HIV and TB as a co-infection.

On many occasions, it was difficult for the research team to ascertain where this need for secrecy lay. There were examples of patients who had requested that their diagnosis not be shared with the family. However, on other occasions, this need for secrecy was left undetermined. Certain members of the CHBC team voiced the concern that they were often uncomfortable discussing the diagnosis. As one nurse commented:

"The HIV status should be known. But as long as we (the 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."

This same nurse commented that often the death certificate would state the cause of death to be TB, even though the health care team knew that the person had died of AIDS. This nurse commented, "I think most of the problems are increasing because of this secrecy".

Lack of Knowledge:

An important issue that pervaded much of the data was ignorance and lack of adequate and accurate information, particularly as it related to HIV/AIDS prevention and care. Health care workers, patients and families, community leaders, traditional doctors, spiritual healers and government agencies were all identified as needing more knowledge and information about HIV/AIDS and other issues related to patient care.

The CHBC team had all received some education about caring for people at home. However, this knowledge base varied, depending on the level of the health care worker. Nurses received basic education in community health and home-based care as part of their nursing training. The family welfare educators received 12 weeks of basic training in community health and home-based care, and the CHBC volunteers received 3 days of official training at the Kgotla (village meeting place), with continued supervision and education by the nurses and family welfare educators. Very few of these health care workers had received education in their basic training that focused specifically on issues related to care and prevention of HIV/AIDS. The nurses, family welfare educators and CHBC volunteers identified a need for continued education on issues related to HIV/AIDS. They believed they could provide better education and care if they, too, were better educated. However, they voiced the concern that continued education was not readily available or, if available, they could
not attend the sessions due to their heavy workload.

One of the most identified needs was for counselling education. The health care workers acknowledged that patients and family members frequently required counselling, however, they felt their skills to be inadequate to meet this need.

Many of the caregivers and family members voiced a lack of knowledge about the patient’s diagnosis, or about how to adequately care for the ill person. When asked about the diagnosis, the caregiver would often give the researcher the patient’s chart. These charts are kept with the patient. It was often through reading the chart that much of the data about the patient’s illness and treatments were obtained. The caregivers were often left ignorant with comments such as “I give him the pills that the nurse gave me. I rub lotion on his sores, and I massage his legs”. Although these caregivers might have provided adequate care, they were unaware as to why certain treatments were necessary. On five occasions, when the medications ran out, the caregiver did not know that she should go to the clinic to replenish the supply. Most caregivers had received rudimentary advice about the use of universal precautions but these precautions were rarely undertaken. The caregivers believed that using gloves and other protective clothing would demonstrate a lack of love for their family member. In addition, the caregivers could rarely articulate the necessity for using universal precautions. They had some vague idea it was to protect them from catching the illness, but had very little understanding about how viruses and bacteria were spread. On one occasion the family caregiver had been taken to a seminar where she was educated about the use of universal precautions in caring for her family member with AIDS. However, she did not receive any gloves at the seminar, and despite asking health care workers for gloves on subsequent visits, she still did not have any at the time of the interview. The research team member provided her with gloves and informed the CHBC team of the need for a continuous supply.

Caregivers also required education about the resources that were available to them. Botswana has excellent resources that are available to people caring for orphans or a sick family member at home. However, data from this study indicated that few caregivers were knowledgeable about these resources. On several occasions members of the research team provided information about existing resources. These resources included free medical supplies and medicines, destitute allowance, support from other NGOs, church groups and others.

Respondents generally agreed that more education was necessary for the community at large. They were concerned that young people were still engaging in unprotected sexual intercourse, and that the prevention messages were not being taken seriously. There was some concern that the posters and media messages were ineffectual. Respondents thought that issues related to HIV/AIDS should be presented in places and in ways that would attract more public attention. Suggestions were given to place video terminals in shopping malls and other locations where people congregate. These videos should portray how people die of AIDS and the dangers of engaging in risk behaviours. Radio Botswana was complimented for providing messages about HIV/AIDS but the respondents considered that this was not enough to really draw public attention to this growing problem. Other suggestions for community education included educating the politicians, village elders, chiefs and
village council, traditional doctors and spiritual healers about the issues related to HIV/AIDS. These education sessions should include the numbers of HIV-infected people in their community, and the rapid spread of the disease. The respondents thought that these community leaders might be ignorant of the devastation that HIV/AIDS is causing within their communities. Meetings should also be held at the Kgotla to raise the awareness of HIV/AIDS, and to educate the community. Finally, the respondents thought that young people should be encouraged to join support groups to educate and support one another on issues related to HIV/AIDS transmission, prevention and care. These support groups were active in some of the research communities but were lacking in other communities.

The research respondents were very concerned with the growing poverty levels that they had either witnessed or experienced as a result of caring for family members at home. However, these respondents did not believe that the government should be solely responsible for alleviating this poverty. They believed that education for income generation should be easily available and accessible to all people. One target should be the education of young people who have dropped out of school or finished their schooling without adequate knowledge or life skills for income generation. In addition, it was suggested that other family members should be taught how to generate income from sales, growing communal gardens, embarking on small manufacturing projects and other initiatives.

The Need for Psychosocial support:

Key informants and caregivers both identified the need for effective interpersonal communication, psychosocial support and the need to promote shared confidentiality. It is important to note that these respondents were not asking for counselling services, but rather that health care workers and others should be educated to perform effective interpersonal communication and provide psychosocial support whenever it was necessary. In particular, families identified the need for bereavement counselling and anticipatory guidance. They wanted to be able to talk about what would happen after their death, who would care for their children, and how the family resources and property would be divided. Families also needed to explore their feelings of grief and loss surrounding the illness. Caregivers described how they were given advice by health care workers, however, they rarely felt they were actively listened to or that their problems and experiences were fully explored. For example, one family welfare educator stated, "we educate them that they need to accept everything". On many occasions the caregivers stated that they had no one to turn to when a crisis or other important life event happened. In fact, when asked who they turned to in times of need, 25 caregivers (71%) said they had no one.

Health care workers also voiced a similar concern. There were times when they found their work to be overwhelming, however, they felt that there was no one to whom they could turn. They two nurses described their feelings as disturbing and becoming internalized to the point where they were considering leaving their jobs.

Key informants such as nurses, family welfare educators, CHBC volunteers and members of NGOs also voiced the concern that they did not know how to provide effective psychosocial support. They were often aware that the caregiver and family
required counselling but they felt inadequate to meet this need. They explained that they had not been educated in interpersonal communication strategies and felt that their skills would be inadequate. Thus they avoided counselling rather than try to meet the family's need. In addition, they reported that there were few counselling services to which to refer families in need. In contrast, one Hospice NGO stressed counselling as an essential component of care. They trained their health workers in interpersonal communication skills and placed a high priority on providing psychosocial support to patients, caregivers and other family members.

Multiple Roles:

Reference has been made throughout this report to the multiple roles that caregivers were required to perform. Family caregivers were often required to care for more than one ill family member. In this research, 8 of the 35 caregivers were caring for (or had cared for) more than one family member. They had watched their loved ones die, often in quick succession. In addition, extended families were becoming blended as children, grandchildren, uncles, aunts, grandparents and orphans joined the immediate family constellation. These multiple roles are highlighted by the experience of one caregiver.

A Case Example: A mother is caring for her daughter who has AIDS. She has previously taken care of three family members who have died of AIDS. There are eight children in the family, two of whom are orphans from her deceased son. The only adults in the family are the mother and her ill daughter. The daughter has four children, and five of the children in the home are attending primary school. The daughter has genital herpes, diarrhoea, confusion, TB, immobility and considerable pain. The daughter is bedridden and her mother describes her condition as very ill and getting worse. The mother has to feed, wash, dress, and take care of the daughter's incontinence. In addition, she carries water, firewood, shops, cooks, does laundry and generally takes care of the young children, the house, and the compound. She also goes to the health clinic to collect medical supplies for her daughter. This mother is still grieving the loss of her other family members and was weeping during the interview. She described her quality of life as poor, and the impact on caregiving as very high.

She explained:

"It really impacts on me because she came here when she was very ill and she is staying here. I hadn’t seen her for a long time, and I didn’t know she was sick. I really have difficulty managing the illness. I can’t sleep and I need pills to help me sleep. I am always unhappy because she is getting worse, because no one can help taking care of this kind of illness. I am getting depressed. I think that the problem is increasing because of the secret. The sores are getting worse, and she complains of pains. Her temperature is very hot now, but she says she feels cold’’.

This mother said that the CHBC team had visited twice, but that she required much greater help. The researcher who interviewed this woman reported this need to the CHBC team.
The Role of Traditional Medicine:

An overview of the role of traditional medicine and spiritual healing was given in the background section of this report. A nurse who had studied traditional healing reported that 80% of people in Botswana turn to some form of traditional therapy in times of need. At the onset of this research, there was no question related to traditional healing on the questionnaire. However, after the first few interviews it became clear that this was an important aspect in people’s lives. Following this realization, the research team actively sought responses to traditional healing practices. Twenty six (74%) of the caregivers described how they sought other remedies and explanations for the illness of their family members. These explanations included being bewitched, having bad blood, being possessed by the devil, and breaking important taboos. The remedies included cutting, inducing vomiting, giving enemas, and applying or ingesting herbs. These families also sought remedies from western medicine and it was a common practice for patients to take pharmaceutical products as well as traditional remedies. The problem arose when families were spending a considerable amount of their scarce financial resources on these traditional consultations. It was not uncommon to pay 400-600 Pula for a consultation, which was far in excess of the monthly family income. Also, some of the traditional doctors and spiritual healers were unscrupulous in their consultations. It should be noted that this was not always the case. However, some families reported that their traditional doctor or spiritual healer had assured the family that they could cure AIDS. This assurance led family members toward false expectations, with an unwillingness to accept the medical diagnosis.

Issues Related to the Provision of Community Home-Based Care:

It is important to stress that this research did not attempt to evaluate or in any way highlight issues related to existing community home-based care. However, in the course of the interviews certain issues arose that need to be addressed. In particular the referral component of CHBC requires urgent attention. In addition, there appeared to be bureaucratic bottlenecks whereby resources, services and supplies were either not known about, or were not reaching families in need. There was considerable debate about the role of retired nurses, family welfare educators and social welfare officers. A debate also questioned whether or not health care workers should be hired specifically for home-based care, or whether all health care workers should be able and willing to work in both institutional and home-based care settings. Concerns were voiced about transportation issues. Finally issues related to respite care and the value of volunteers and family welfare educators were raised. Each of these issues will be addressed in detail.

Referral: The Ministry of Health in Botswana developed a triplicate form to be completed when a patient is discharged from the hospital. This form contains information on the patient’s medical condition, the care that is required for the patient at home, and the general condition of the patient on discharge. Coordinators have been hired to harmonize the process of referral and liaise between the hospital and the community. Despite these efforts, referrals are either very slow in reaching the community health clinics, or they are non-existent. Many of the nurses stated that people were discharged home without their knowledge. Nurses, CHBC volunteers
and family welfare educators often heard about the patient through informal channels. In addition, the diagnosis was rarely available, and the health care workers relied on the patient and family to assess the patient’s need. As one nurse commented, “the referral system stinks”. Health care workers suggested that CHBC has become a “dumping ground” because the system is so uncoordinated.

Although this research did not study the TB DOTS Programme (Direct Observation Therapy Services), it would appear there might be ways to integrate or coordinate DOTS with CHBC to better use scarce resources. The DOTS Programme provides a service whereby the patient is supervised in taking TB therapy. This supervision can be at a health care facility (if the patient lives close to one), or in the community if the patient lives in a more remote area. During this research, there was evidence of family welfare educators and nurses participating in the supervision of TB therapy. One nurse suggested that care for patients and their families living with HIV/AIDS and other chronic illnesses could be “piggy backed” with DOTS to provide better community home-based care and referral. This comment was made because of the high incidence of HIV/AIDS with TB as a co-infection.

Debate About Roles: The CHBC Programme was conceptualised as an integrated programme, however, there is considerable debate about whether this approach is working. Some nurses interviewed felt that only people who wanted to work in home-based care should work in the community. They argued that community home care required a certain set of skills, and that only nurses who enjoyed this kind of work should be hired. Conversely, others (including the Ministry of Health) consider that all health-care workers should be able and willing to work in both the community and the hospital settings. They argued that in order for CHBC to be a seamless programme, health-care workers should be familiar with, and capable of working in both settings. At the time of the interviews, these views had not been reconciled, and many of the health-care worker respondents felt that breakdowns in the system was due to this controversial debate.

Lack of Resources: Supplies and resources for people in home care are available in most areas of Botswana. When a community is registered with the CHBC Programme, medical supplies and other resources are made available to that community. It should be noted however, that soap and detergent are not considered a medical supply and therefore these supplies are not given to the families. Only people on destitute allowance qualify for soap. During this research, there were repeated requests for soap and detergents. It was noted that family welfare educators and CHBC volunteers often carried soap that they had bought themselves. The research team also noted other occasions when needed resources were not available. This lack was reported to the CHBC team, and the situation was usually rectified. There appeared to be two issues that compounded this problem. First, many caregivers and other family members did not know that they were eligible for these resources. This lack of information appeared to be tied to the faulty referral system. Once the family knew they were eligible for resources, they made requests of the CHBC team. The second issue appeared to be caused by bureaucratic bottlenecks. An example was of an HIV-positive mother and baby discharged from hospital. The social worker at the hospital had written a letter to be given to the health clinic to request the child be provided a high-protein supplement and milk. This request had been made three
months prior to the research team interview. However, the family had not received these resources. This is an extreme example, but there were other similar examples where people had been educated to use gloves when caring for their family member, but these gloves had not been given to the family.

Of greatest concern was the length of time that the destitute allowance took to be processed. Once a family was thought to need destitute allowance, this referral went to the social welfare officer. The officer then did an assessment and sent the form to the appropriate government agency. There were examples of this process taking up to three months. In the meantime, the families often went without adequate food and other material resources.

**Retired Health Care Workers:** According to an official at the Ministry of Health, there was an additional 25 million Pula (approximately $6 million) put into the system to hire an additional 160 nurses, 180 family welfare educators, and 30 social welfare officers. In order to fulfill this requirement, the government hired retired health-care workers. Key informants in this research (in particular, nurses, members of NGOs, family welfare educators, and CHBC volunteers) complained of this hiring process. It should be noted that the interview schedule did not directly ask a question about this issue. Rather, the issue was raised when the question, “Is there anything else you would like to add?”, was asked. It was the retired nurses that drew the most complaints. Respondents reported that the retired nurses were unable to physically care for people in their homes. In addition, these nurses were reported to be unable to walk the long distances often required to reach certain homes. Some CHBC volunteers complained that the nurses sat in the home and directed the volunteers to do certain tasks without helping or demonstrating those tasks. However, this was not the view of all respondents. Other respondents considered the nurses to be an asset to the programme. They believed that the retired nurses brought a wealth of experience and played a crucial role in CHBC. It would appear that certain nurses were having difficulty returning to work, and respondents reported on these nurses. However, there were other nurses that functioned well in their new roles. According to one senior member of the CHBC Programme, the hiring of retired nurses is up for review at this time.

**Transportation:** Issues of transportation were of considerable concern to most respondents in this study. There were two issues that dominated this concern. The first was the cost and availability of transportation for patients and family members to go to hospital when necessary. The second concern was the need for transportation for health and social welfare personnel to reach all the communities in their district. Vehicles are not common in many parts of Botswana. Many families rely on donkey carts, bicycles, scooters and walking. When a person requires hospitalization, the cost of this transportation is borne by the family. There were reports of 100 Pula (approximately $26) to transport a family member. This cost is frequently as much as the family’s monthly income. Therefore, people were reported to remain at home when hospitalization would be the appropriate form of care. In addition, health and social welfare personnel were reported to be limited in their activities by lack of transportation. The larger centres with CHBC had excellent transportation services. However, the smaller, less-well served areas were often without adequate transportation. One of the villages visited by the research team had no form of
community transportation. Patients walked or rode a cart to the health post; the nurse, family welfare educators and CHBC volunteers walked to visit their families. This meant that families that lived at a considerable distance from the health facility received little, if any support from the CHBC team. The social welfare officer lived in an adjoining village and there was no transportation to assess the destitute needs of people in this village. One member of the research team drove the welfare officer around the village so that the destitute allowance applications could be made. It should be noted that this village is in the process of applying for CHBC registration. It is hoped that once this application is approved, that adequate transportation will be forthcoming. In addition, the Ministry of Health is piloting a transportation project whereby scooters and bicycles will be allocated to certain communities. However, there is some concern the sandy and muddy roads of most communities will make this form of transportation problematic.

**Respite Care:** As this research will attest, the burden of care for home-based family caregivers is immense. Caregivers are themselves dying after caring for family members. Although no figures were available of this caregiver mortality, it is certain that help is required to ease the burden of care. Certainly the CHBC team provides a much-needed service. However, many caregivers and key informants suggested the need for respite services. Two suggestions were made. The first was that a facility be made available where sick family members can be taken for a short stay to provide respite to the caregiver. The second suggestion was that CHBC volunteers be trained to receive sick family members into their own homes for a short period of time. There was also a suggestion that patients should be placed in a "half-way house" between hospital and home where family members can be trained to care for their sick family member at home.

**Enhancing the Role of the Family Welfare Educator:**

There was general agreement in this study that the family welfare educator played a vital role in CHBC. Still, respondents thought that this role could be further enhanced. They suggested that the family welfare educators be educated to provide effective psychosocial support. It was evident from this research that the family welfare educators provided effective information and advice. However, psychosocial support was identified as a pressing need, and respondents thought that these workers, together with nurses and volunteers, should be educated to undertake a counselling role.

**Expanding the Role of Volunteers:**

At this time, CHBC volunteers are mostly women, and they mostly help with the care of families in their homes. Respondents in this study thought this role should be expanded to include more men and to expand the volunteer roles that are undertaken. For example respondents suggested that men could help with needed house repairs, or to help build new houses when necessary. They also thought that men and women could be trained to care for community gardens so that needy families could receive fresh produce. In addition, male volunteers could take on some of the roles that the men of the family used to do such as ploughing, seeding, harvesting, and tending cattle. These roles are being lost in some families as the
young, productive members of the family die of AIDS. Finally, the respondents thought that volunteers could be encouraged to adopt orphans where the extended family is unable to assume this role.
SUMMARY

This research was an exploratory study undertaken to examine and describe the experiences and perceptions of family caregiving for people living with HIV/AIDS and other chronic illnesses cared for at home. In particular, this study focused on the impact on older women, youth and children as primary family caregivers. Three districts in Botswana were chosen as study sites. The locations were diverse enough to gain insight into issues related to rural and urban life.

The results of this study point to some important findings. The burden of care on older women and younger girls is profound. They have to assume multiple roles that are often overwhelming. The experiences of poverty exacerbate these problems. 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 an important role in many of the families interviewed, however, the costs of service can be crippling to people already living in poverty. Finally, some issues related to the provision of CHBC were highlighted.
LIMITATIONS OF THE STUDY

Although this study provided important insights into the experiences, perceptions and impact of family caregiving for people living with HIV/AIDS and other chronic illnesses, certain limitations exist.

As a qualitative research study, the decision on how many people to interview rested on reaching data saturation or redundancy (Lincoln & Guba, 1985). Members of the research team believe that data saturation was achieved. The team began to hear the same issues repeated by research respondents, sometimes on many occasions. Therefore, it appeared that 70 interviews provided enough data to be confident that results adequately represented the experiences and perceptions of the research respondents. However, in keeping with the tenets of qualitative research, no claims to generalizability of these findings can be made. (Huberman & Miles, 1994) Generalizability is considered in light of the “fittingness” or “applicability” (Sandelowski, 1986) of the research results to other populations of caregivers engaged in home-based care to people living with HIV/AIDS and other chronic illnesses. That is, reliability and validity of the research depends, to a large extent, on testing the “fittingness” or “applicability” of the findings to other study populations. It is, therefore, important to replicate this study in other countries with other research respondents. Replication would contribute to the limited body of knowledge about the impact of family caregiving in home-based care, and would strengthen the importance of the results. Comprehensive strategies and guidelines could then be developed to provide adequate support and care to caregivers, family members and patients being cared for at home.

Only two young women were interviewed as primary caregivers. The original intention was to interview only primary caregivers and key informants. However, it became apparent that young girls played an important supportive role to the primary caregivers, and their experiences were not captured first hand by the researchers. Important data on this issue came from the key informants and some of the primary caregivers; this research should be expanded to collect first-hand information about the experiences of young girls who play a supportive role in home-based caregiving.

Some key informants reported that young girls were unwilling to play a supportive role in caregiving. It was reported they would rather go out drinking and to discos than care for family members. This information could not be verified. It would be important to interview young people to ascertain their views. Therefore it is essential that future research interview young people in order to understand their perceptions, attitudes toward, and experiences of family caregiving.

In the section on access to participants, suggestions were made as to why all caregivers who were approached to participate in this study agreed to be interviewed. However, the question remains as to whether these caregivers felt vulnerable about the care they might receive from the CHBC team should they refuse. This issue was discussed between the research team and the CHBC workers. It was concluded that no coercion or undue influence was applied. However, sensitivity to these issues is crucial in any future research.
This research investigated the impact of family caregiving for people with HIV/AIDS and other chronic illnesses. Fifteen respondents cared for someone with HIV/AIDS, while 20 respondents cared for a person with other chronic illnesses. Although it would appear that much of the impact on caregivers is similar, regardless of the patient's illness, this cannot be verified. For instance, issues of stigma and the secrecy surrounding HIV/AIDS might not apply to caring for other chronic illnesses. In this study, home-based care was associated with HIV/AIDS, so issues of stigma existed regardless of the patient's diagnosis. In contrast, secrecy surrounding the patient's diagnosis was considerably different. On the whole, caregivers caring for a person with a chronic illness were able to identify the diagnosis, whereas caregivers caring for a family member with HIV/AIDS were mostly unaware of the diagnosis. Future researchers might consider comparing these populations and analyzing the similarities or differences for family caregiving.

The interviews with caregivers were conducted in Setswana and the responses recorded in English (see research integrity section for details). The research team believes they took extraordinary steps to ensure that the data fully represented the experiences and perceptions of the caregivers. However, it is possible that details were lost in translation. Debriefing sessions and full discussions among the research team at frequent intervals attempted to alleviate this problem, but it must be recognized that some detail could have been lost.

The principal researcher and author of this document is not from Botswana. Every effort has been made to understand and capture the cultural, traditional and contextual elements of this study. Nevertheless, it is possible that some misunderstandings and misconceptions still remain. A first draft of this document was sent to the research team for corrections, elaborations and suggestions. This final document reflects that feedback.
RECOMMENDATIONS

Based on the results of this exploratory study, the following recommendations are made:

➢ **All** research that involves community action should be housed within an action-research philosophy. The effects of this exploratory study have already been noted in some small actions that were taken at the community level. It is hoped that the results of this exploratory study will promote further action.

➢ The principles of individual and community empowerment should underpin all community initiatives, including research and evaluation. Respondents of this study emphasized the role of the community in identifying their own problems and seeking their own solutions. This is not to say that governments and other organizations should not aid this process, however, communities (including their leadership) should play a central role in any initiatives. In Botswana, the Kgotla (community meeting place) could play a vital role in this community mobilization.

➢ The referral system between hospital and home and vice-versa requires strengthening. It is important that there be integrated continuum of care.

➢ Future research related to family caregiving in home-based care should explore ways of linking and possibly integrating the TB DOTS Programme with CHBC so that scarce resources can be better utilized. Patients and family members require further education about care of the patient at home and about accessing needed resources.

➢ There should be minimum set standards that provide information on universal precautions including wound care, use of gloves, masks and other barrier methods.

➢ Strategies should be considered to support young girls remaining in school despite their caregiving roles and responsibilities.

➢ Issues of family poverty must be addressed so that young girls will not be tempted or forced to engage in sexual relationships in exchange for money or material goods.

➢ Volunteers and other community workers need to be honoured for their contribution. CHBC volunteers received 100 Pula a month, have a special bag, tee shirt and umbrella. Other forms of incentive could be considered for other community workers. People remain committed to a project when they feel valued for their contribution.

➢ The role of community volunteers could be expanded and men should be encouraged to join the programme. Volunteers could be encouraged to assist in income generation, assistance with farming and with building of and repairing homes.

➢ There is an identified need for greater psychosocial support within the community. To that end, education on effective interpersonal communication skills and counselling should be initiated. In addition, supervision and continued support should be made available for nurses, family welfare educators, social welfare officers and CHBC volunteers. Peer counselling and support group formation should also be encouraged.
CHBC team members require continued education and supervision. In particular, issues related to HIV/AIDS prevention and care should be emphasized. Education on other community- and home-based care issues should also be made available to these workers.

There should be joint education sessions between traditional doctors, spiritual healers and members of the CHBC team. These education sessions would improve the knowledge of these health workers, and would also help create a better partnership between traditional and western medicine.

Education sessions on income generation should be offered to community members. In addition, micro-credits systems or initiatives should be explored and be made available.

Some of the government funds available for CHBC could be expanded to support the home-based care initiatives of NGOs. It is important that services not become duplicated, however evidence from this research suggests that certain NGOs provide a particular service not available in conventional CHBC. Palliative and terminal care is one such example.

Better coordination between governmental CHBC and NGOs involved in home-based care should be encouraged.

Strategies related to respite care should be explored.

Resources and supplies should be distributed quickly and regularly. The bureaucratic process requires streamlining. In particular there should be an adequate supply of soap, detergents and disinfectants.

Vehicles for transportation need to be made available to all villages. This transportation could be from donations, sponsorships or from government funds.

The issues of stigma and secrecy surrounding HIV/AIDS must be addressed. Politicians and other community leaders should be encouraged to become actively involved in openly addressing HIV/AIDS stigma. In addition, public participation should be encouraged to address issues related to HIV/AIDS prevention and care.

This research study should be replicated to ensure consistency and accuracy, and to broaden the scope of these findings. Future studies should be done in different study locations (i.e. different countries).
CONCLUSION

This exploratory study has provided an important contribution to the limited literature on the impact of caregiving on older women, youth and children. It is hoped that this research will now be expanded to other parts of Botswana and to other countries where HIV/AIDS is endemic. As an action-research project, this study has already provided some assistance to people living and working in CHBC. It is hoped that an expanded study will further this contribution. In particular, the objectives of an expanded study would be to (a) develop sustainable effective strategies and/or interventions to improve the quality of care for people living at home with terminal/chronic illnesses, (b) ameliorate the negative impact on caregivers, (c) retain informal caregivers as a valuable resource, complementing the formal health-care system, (d) reduce the negative impact of "lost" opportunities for the future (including foregone schooling for children/youth, and economic/social security for all caregivers), (e) increase patient and family caregiver's quality of life, and (f) develop recommendations for policy related to caregiving by children, youth and elderly women. This study was a first step in achieving these broad objectives. It is hoped that future research will support the development of CHBC as an integral part of the health and social system, promote an improved quality of life for caregivers, while improving the care for people with chronic and terminal illnesses in home-based care.
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APPENDIX A

The Effects Of Providing Home-Based Care To A Family Member Living With HIV/AIDS And Other Chronic Illnesses: Botswana March-April, 2000

Thank you for agreeing to be part of this exploratory study investigating the experiences of home-based family caregiving on children, youth and elderly people. The information we collect will not identify you in any way, and there will be no adverse consequences to you from your participation in this study. The information we collect will become part of a report that will be shared through the World Health Organization and distributed to people who are interested in family caregivers experiences of home-based caregiving.

The purposes of this study are to:

- explore and describe the phenomenon of home-based caregiving to family members living with HIV/AIDS and other chronic illnesses by children, youth and elderly women.
- raise awareness of home-based family caregiving, particularly in relation to forgone opportunities for a satisfactory quality of life for children, youth and elderly women
- develop sustainable effective strategies/interventions to improve the quality of life for these home-based family caregivers
- develop sustainable effective strategies/interventions to improve the quality of care

Community: ________________ District: ________________ Date: __________

Name of Researcher: ____________________________________________________

Is the community  (a) Urban? (b) Rural? Please circle one.

In your opinion, what is the socio-economic status of this family? Please circle one.  (a) Poor? (b) Middle class? (c) Wealthy?

Please describe the dwelling, type of sanitation, water supply, heating, lighting etc.

________________________________________________________________________

Information on Respondents: Please circle which role best describes you:

Primary home-based family caregiver.

Person living with HIV/AIDS/other chronic illness

Young girl (6-18) residing in the home

Volunteer/Member of a CBO or an NGO.

How long have you been doing this work? __________________
Gender?  M  F  Please circle one.

What is your age? ____________________________________________
What is your occupation? ______________________________________
Years of education (including basic schooling and advanced education)? ______

Demographic Characteristics of the Family and Family Caregivers:

1. Please include all the family members living in this household.
   Circle all the members in the family and state their age:

<table>
<thead>
<tr>
<th>Family Member</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Father</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td></td>
</tr>
<tr>
<td>Brothers (state how many, including age)</td>
<td></td>
</tr>
<tr>
<td>Sisters (state how many, including age)</td>
<td></td>
</tr>
<tr>
<td>Grandmothers (state relation to father or mother, including their age)</td>
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<tr>
<td>Grandfathers (state relation to father or mother, including their age)</td>
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</tr>
<tr>
<td>Aunts (state relation to father or mother, including age)</td>
<td></td>
</tr>
<tr>
<td>Uncles (state relation to father or mother, including age)</td>
<td></td>
</tr>
</tbody>
</table>

Other family members, please specify, including their ages:
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

2. What is your relationship to the person living with HIV/AIDS or other chronic illness?
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
3. Do you have other activities outside the home e.g. work, school etc.? Please state.

4. What illness does this patient have?: (a) HIV/AIDS, or (b) other chronic illness Please circle one.

5. (If this illness is not AIDS) what is the diagnosis? ______________________

6. How long has the patient had this illness? When was it first diagnosed?

7. How ill is the person with HIV/AIDS or other chronic illness? Please circle one.  
   (a) very ill  (b) moderately ill  (c) fairly well

8. Is the illness getting: (a) worse  (b) better  (c) remaining the same  
   Please circle one.

9. What are the main symptoms of the illness?

10. What do you believe caused the illness?

11. Has the patient and/or family been isolated or stigmatized as a result of this illness?  
    Yes  No  Please circle one.  
    If yes, give an example:

12. What kinds of crises happen in this family? When and where do crises happen?  
    Please give an example:

13. Which family member takes charge if a crisis happens? Please provide the name  
    and their relationship to the family.
14. Where do family members go to seek advise in providing care for the person living with HIV/AIDS or other chronic illness? Who gives the advice?

Treatment Variables

15. How many hours of home-based family caregiving do you do each day? ______

16. How long has the patient needed this home-based family caregiving?

17. What treatments have to be given?

18. Can you carry out the treatments that are required? Yes No Please explain: Please circle one:

19. Support Resources

20. Does anyone outside the home and family help with giving treatments? Please state how many, and give details about their role (e.g. Volunteer, neighbour, health worker etc)

21. Do other family members play a role in patient care? Please describe:

22. Are NGO's involved? If so, which ones, and what services do they provide?

23. Are formal health care workers involved in patient care? Yes No
24. Is the formal health care worker involvement adequate? Yes No

25. What health supplies (medicines, dressings, equipment, gloves, etc.) are needed? Please identify:


26. What health supplies do the patient and family receive (e.g. Medicines, equipment, soap, gloves, dressings etc.)?


27. What other important life events are happening in the family (besides the illness) that impacts on care? (e.g. People moving into the family, other injuries, illnesses, births, deaths, changing family constellation etc.)


Actual Caregiving Involvement

This section provides information about the level of care that is required. Please answer by circling the words ‘none’, ‘minimal’, ‘moderate’ or ‘complete’ that best describe the level of care. Please circle one word only.

28. Activities of daily living (ADL)
   How much help does the patient need with feeding?
   None Minimal Moderate Complete
   How much help does the patient need with washing?
   None Minimal Moderate Complete
   How much help does the patient need with dressing?
   None Minimal Moderate Complete
   How much help does the patient need with mobilisation?
   None Minimal Moderate Complete
   How much help does the patient need with elimination?
   None Minimal Moderate Complete

29. How much help does the patient need with instrumental activities of daily living (IADL)? Please answer by circling the most appropriate worddescriptor.

   How much help does the patient need to get water?
None | Minimal | Moderate | Complete

How much help does the patient need with cleaning/sanitation?
None | Minimal | Moderate | Complete

How much help does the patient need with getting supplies?
None | Minimal | Moderate | Complete

How much help does the patient need with shopping?
None | Minimal | Moderate | Complete

How much help does the patient need in dealing with money/finances?
None | Minimal | Moderate | Complete

How much help does the patient need with getting health care supplies?
None | Minimal | Moderate | Complete

How much help does the patient need with cooking?
None | Minimal | Moderate | Complete

How much help does the patient need with collecting firewood?
None | Minimal | Moderate | Complete

30. What do you do when you provide care to the patient? Please give an example.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

31. What kind of emotional support do you give to the patient? Please describe with specific examples.
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

32. What other roles do you perform? (e.g. Parenting role, working outside the home etc.) Please provide specific examples-
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

33. What are the treatments prescribed by outside authorities? (e.g. Diet, medications, exercise, physiotherapy, other physical treatments etc.)
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
34. What care do you do that is prescribed by outside authorities (e.g. Health care workers, doctors, traditional healers, etc.)?

________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________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39. Are these symptoms managed well?  (a) Yes  (b) No  Please explain.

40. How much do you know about how to carry out the treatments?  What form of instruction have you received?

41. What support mechanisms/resources are there?  (e.g. Gloves, water, disinfectants, medical supplies, medications, disposal of waste etc).

42. What do you know about maintaining personal health and preventing physical harm to yourself?

43. In your opinion, what word would you use to describe the level of satisfaction you think the patient feels with the family caregiving he/she receives?  Circle one:  Very satisfactory  Somewhat satisfactory  Unsatisfactory  Please explain.

**Impact on Family Caregivers**

44. How would you rate your quality of life?  Please circle one.

Very poor  Poor  Neither poor nor good  Good  Very good

45. Circle the word that best describes the impact that caregiving has had on you.

High  Medium  Low  Please provide an example.
46. Circle the word that best describes your level of satisfaction at being a home-based family caregiver? Circle one.
   High      Medium      Low      Please provide an example:

47. (If the caregiver is a young person) What is the impact of caring on their schooling or ability to seek employment? Please explain.

48. (If the caregiver is an older person) What has been the impact of family caregiving on your financial, physical, and/or social well being? Please explain.

49. What kind of support do you need for yourself?

50. Who do you turn to for support for yourself? Do you receive the support you need?

51. Some people get depressed when they have to care for others in the home. Has this happened to you? Please explain.

52. Caregivers often find that providing care to a family member impacts on their ability to have friends and/or join in social events outside the home. Has this happened to you? Please explain.
53. What is the attitude of other people toward you as a caregiver? Please explain.

54. Some people say that the role of family caregiving affects their feeling of spirituality. Has this happened to you? If so, please provide an example.

55. Some people say that the role of family caregiving affects how they worship. Has this happened to you? If so, please explain.

56. Some people start to abuse substances such as food, alcohol, drugs (legal and illegal), and tobacco etc. Has this happened to you? If so, please explain.

Strategies for Action (all respondents)

57. In your opinion, what strategies need to be in place to provide support to family caregivers in home-based care?
58. How can we begin to put these strategies into action?
APPENDIX B
KEY INFORMANT* INTERVIEWS

Thank you for agreeing to be part of this exploratory study investigating the experiences of providing home-based family caregiving on children, youth and elderly people. The information we collect will not identify you in any way, and there will be no adverse consequences to you from your participation in this study. The information we collect will become part of a report that will be shared with the World Health Organization and distributed to people who are interested in family caregivers experiences of home-based caregiving.

The purposes of this study are to:

- explore and describe the phenomenon of home-based caregiving to family members living with HIV/AIDS and other chronic illnesses by children, and youth and elderly women
- raise awareness of home-based family caregiving, particularly in relation to forgone opportunities for a satisfactory quality of life for children, youth and elderly women
- develop sustainable effective strategies/interventions to improve the quality of life for these home-based family caregivers
- develop sustainable effective strategies/interventions to improve the quality of care

Position/Role: ________________________________________________________________

How long have you been in this position: ____________________________

1. Please tell me about your work in the area of home-based care? (probe here for issues related to young girls and older women as family caregivers).

* Key informants to include: social workers, health care workers, home-based carev(HBC) coordinators, HBC managers, National Health Research Unit, Ministry Officials, HIV/AIDS researchers

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2. In your opinion, what are the major problems encountered by older women as family caregivers?

3. In your opinion, what are the major problems encountered by young girls as family caregivers?
4. What resources are there in the community related to family caregiving?

5. In your opinion, what strategies need to be in place to provide support to family caregivers in home-based care?
6. In your opinion, how do you think these strategies can be put into action?

7. Is there anything else you would like to add about the issues of family caregiving by children, youth and elderly women in home-based care?