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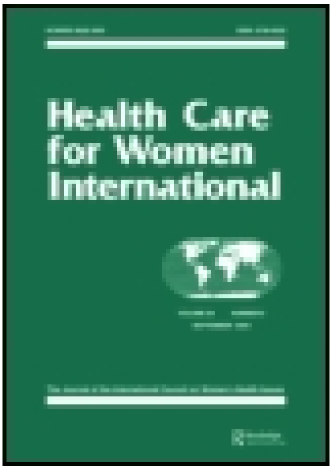

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Family Caregivers in Rural Uganda: The Hidden Reality

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Family Caregivers in Rural Uganda: The Hidden Reality

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We conducted 16 in-depth interviews with family caregivers of AIDS patients in three rural districts in western Uganda. They were selected from a client visitation list of the home-based care program for AIDS patients, based on volunteer participation. Family caregivers reported huge problems associated with providing the necessary psychological, social, and economic care. They also said that the physical and emotional demands of caregiving are overwhelming daily challenges. Most support to AIDS patients provided by family, friends, and the churches. The study highlights the great burden of caregivers, in sub-Saharan Africa who most often are elderly women and young girls.

This study examine, the burden and related health issues of family caregivers, primarily women, for AIDS patients in Uganda. It was part of a broad research project using qualitative methods on family caregiving in the home environment in sub-Saharan Africa. As the requirements for family care giving are often overwhelming for women under the conditions as they exist in Uganda and in other developing countries, it constitutes a

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gender issue of great importance that has not been appreciated fully in the international literature. Family caregiving is also of international relevance, as HIV/AIDS is a global pandemic of previously unknown proportions. In many poor countries, family caregiving is the most common and often the only care that AIDS patients receive, because clinic-based care often is not available close to home or is not affordable. Therefore, family caregiver support programs to alleviate this burden are essential for all those countries where HIV/AIDS is prevalent. Family caregiver burden encompasses medical, social, and economic issues at the household level, which requires an interdisciplinary approach in order to fully understand and appreciate the different dimensions of the family caregiver burden and its negative impact on the lives of so many women in so many countries.

Many persons affected by HIV/AIDS in sub-Saharan Africa remain at home and receive either some care through hospitals or home-based programs or they receive no formal health care services at all. The main burden for their care rests almost entirely on family members, which poses tremendous challenges and sacrifices to these caregivers. The challenge and importance of the family caregiving task for AIDS patients is not reflected in HIV/AIDS programming, where a program component for care of the caregiver is absent in many national HIV/AIDS plans.

Most often the burden of care for AIDS patients falls on the female family members who in Africa traditionally are considered the principal caregivers (MacNeil, 1996; Olenja, 1999). This adds enormous responsibilities and stresses primarily on women in a society where women already are overburdened with their responsibilities for the general health of their families, for household food security, for their children's welfare/education, and for managing scarce resources. Furthermore, AIDS patients and their family caregivers in sub-Saharan Africa live in communities where stigma surrounding HIV infection exists and where that strong stigma is an added burden for the family caregiver (Kalondo, 1996; Anderson, 1994).

Family caregiving is emphasized as a crucial service, especially in poor rural African settings where formal health care services are virtually absent (Chela, Campbell, & Siankanga, 1989; Ntozi, 1997; Reijer, 1999; Robson, 2000). A few studies have addressed issues facing family caregivers for AIDS patients. For example, Brouwer and colleagues (2000) and MacNeil (1996) described in their work the struggle and difficulties of Buganda women in Uganda of providing love and care for their relatives with HIV/AIDS. Brouwer also observed in Uganda that mothers who care for their children with HIV/AIDS had a heavy emotional burden that prevented them from following the advice given to them by health care workers and from delivering proper care for their children (Brouwer et al., 2000). Ndaba-Mbata and Seloilwe (2000) reported that family caregiving in Botswana was inadequate because family caregivers were not trained to provide basic care. Olenja (1999) found that training in AIDS care was grossly lacking at the community and household level in Kenya, where AIDS caregivers were worried about their lack of skills, yet they had to care for their relatives. In South Africa it was reported that caregivers of children with AIDS had a great knowledge gap in providing appropriate primary care for the affected children (Zimba & McInerney, 2001). Robson (2000) observed in Zimbabwe that young girls disproportionately were burdened with caregiving responsibilities for family members with AIDS, which robbed them of their education and negatively affected their career options. From Botswana, it was shown that family caregivers for AIDS patients mostly were younger girls and older women (Lindsey, Hirschfeld, & Tlou, 2003).

In areas of sub-Saharan Africa, where home-based care services were reported to exist, these services often were overwhelmed with the patient load, because they were understaffed and under resourced. Also, it was reported from Uganda, that home-based care health care services were not always accessed by families because family caregivers did not know about these services. In addition, there was generally little help for family caregivers from other family members, friends, or neighbors (Ntozi, 1997; Seeley et al., 1993). Jackson and Kerkhover (1996) and Mc Donnell and colleagues (1994) supported the findings by Ntozi (1997) and Seeley and associates that home-based care services in sub-Saharan Africa often are defeated in the attempt to provide adequate services because of a lack of capacity to deliver this service in an appropriate fashion and in a client-oriented way. They concluded that new approaches are needed and have to be developed in order to solve the family care issues as described in the literature (Jackson & Kerkhoven; McDonnell et al.).

These studies highlight the enormous difficulties family caregivers of AIDS patients face in their attempt to provide satisfactory and passionate care without professional assistance. In order to fill in the gap of knowledge on how African families provide care and what they experience in the provision of care to their patients, we conducted this study in the Kabarole, Kamwenge, and Kyenyoyo districts located in western Uganda. The study was designed as an inductive qualitative study that addressed the feelings, beliefs, and understandings of the caregivers themselves about their plight and situation. In this study we had the following specific objectives:

1. to assess the family caregiver burden associated with HIV/AIDS care in rural districts in western Uganda;
2. to determine which coping strategies are used by family caregivers in their provision of care for AIDS patients;
3. to make recommendations for reducing the family caregiver burden for AIDS patients.

BACKGROUND INFORMATION

Kabarole, Kyenyoyo, and Kamwenge districts have a home-based care program that consists of formal and informal parts. The formal part is made up of professional, government-paid nurses who are based at the nearest health center and who visit the homes of patients who have been admitted to the program. The informal part of the program is composed of family members who are the principle caregivers for the AIDS patients at home. Home care nurses deal only with the care for the AIDS patients and not with personal issues of the family caregiver. In the past few years, home visits of professional nurses have declined due to funding shortages of the Kabarole Health Department. Before funding cuts were introduced, the home-based care program coverage reached only an estimated 35% of homes requiring care. The HIV prevalence in the sexually active population is high and estimated to be around 14% in the districts. An estimated 4,200 AIDS patients require clinical care in the Kabarole district alone. The districts are typical for sub-Saharan Africa, with a high burden of infectious diseases, including malaria, tuberculosis, and parasitic infections. All homes visited during this study had no running water and no electricity, and were built poorly, with thatched roofs, mud walls, and earthen floors. Generally, home-based care programs are very much limited in Uganda and, to the best of our knowledge, there was no information on any formal programs targeting family caregiver support.

As HIV/AIDS affects mainly the sexually active age groups in their economic prime time, the deaths of younger adults in the families, who often are the breadwinners, pose specific social and economic challenges for affected families. In addition, spouses as family caregivers for AIDS patients often are aware that they are very likely HIV positive too, which contributes even more to their stress, as they see their own future unfolding in front of their eyes.

METHODS

The study was conducted in July 2003 in four areas located in the three western Ugandan districts. The areas selected were Kibiito and Kataraka subcounties in the Kabarole district, Kahunge subcounty in the Kamwenge district, and Kaihura subcounty in the Kyenjojo district. The study was designed as a qualitative study with content analysis.

Sample Selection

The participants were recruited using the active client lists of the home-based care program for AIDS patients in the four subcounties. Only participants with care experiences of at least one year or longer were selected from the list for the year 2003, starting at the beginning of the list and then selected if they qualified. The subcounties that were selected were located in a wide geographic range of rural Uganda with different demographic patterns and cultural practices. The number of family caregivers (14) was arbitrarily set, because it was felt that this would give us enough information about the topic. A total of 16 caregivers were interviewed: 12 females and 4 males.

The median age of 12 female participants was 46.5 years (range 19 to 73 years). The ages of the 4 male caregivers were 40, 52, 60, and 63 years. Five caregivers were below 40 years, 4 were between 41 and 50 years, and 7 were over 50 years. Ten were married, 2 were divorced or widowed, and 4 were single. Eight of the care recipients were siblings, 3 were either spouse or parent, while the remaining were grandparents. Four caregivers had provided care for fewer than 2 years, 6 caregivers said that they were care providers for 2 to 5 years, and 6 caregivers said they had provided care for more than 5 years.

The study was approved by the Health Research Ethics Board at the University of Alberta, Edmonton, Canada; the National Council of Science and Technology, Kampala, Uganda; and the District Directors of Health Services in the districts involved. Written information letters outlining the purposes and implications of the study, and clarifying that participation was completely voluntary, were provided or read to participants. The content of the information letter was explained thoroughly, concerns were clarified, and participants were requested to give their consent by signing the consent form. Participants who could not write gave a fingerprint on the consent form.

Development of Interview Tool

A guide for the in-depth interviews was developed to explore the experiences of the caregivers. The guide included topics around home-based care issues such as caregiving tasks and burden, caregiving training, relationship with service providers, housing conditions, juggling responsibilities, financial costs, personal health, relationship with care recipient and other family members, and planning for the future. The topic guide also included additional information related to the respondents' role as caregivers and its effect on their lives, communities' attitude to families and caregivers of AIDS patients, knowledge of available treatment options, coping mechanisms, and role of men in care provision. The locations of the interviews are shown.

Data Analysis

All in-depth interviews were tape recorded after consent for recording was given by participants. Transcriptions from the tape were done word

TABLE 1 Composition of in-depth interviews with family caregivers in the four study areas

Kibiito subcounty	Kahunge subcounty	Kaihura subcounty	Kataraka subcounty
4 females	3 females 1 male	2 females 1 male	3 females 2 males

by word in the local Rutooro language. Transcripts in Rutooro were translated into English by an experienced language teacher. All translations of transcripts were reviewed by a second interpreter and compared. Differences between both interpreters were discussed and corrected. The qualitative analysis used the English version of the transcripts. We trained two local interviewers/facilitators, one male and one female, who took notes about content, facial expressions, and body language. Qualitative analytical techniques included content analysis (theming, coding, categorizing, abstracting). Abstracting was done by transforming data from individual instances to create general categories that were derived from the data.

RESULTS

Five main themes were extracted from the transcripts: (1) how to become a caregiver, (2) caregiver's burden, (3) coping with the caregiver burden, (4) lack of knowledge and skills of the caregiver in care provision, and (5) support for caregivers. All participants universally expressed their very high burden of care and its negative impact on their physical and psychological well-being. In contrast to this high care burden, informal or formal support for caregivers was very limited. In spite of home visits of nurses, all the family caregivers felt that they did not have the basic knowledge and skills to provide what they thought would be adequate care for their patients.

Becoming a Caregiver: The Roles of Male Family Members

Although the role of caring for the sick in households is considered primarily a woman's responsibility, responses from the interviews indicated that in some situations any member of the family, irrespective of their age or sex, takes up this role. To the question of whether men usually are involved in the caregiving role, some participants said this would happen if the patient feels comfortable with the person or in the absence of a woman:

> In fact, I realized it when my brother was sick and the wife could not take care of him, I was forced to leave work and start nursing him until he died. (male caregiver, 40 years)

> Sometimes men find themselves alone without people to assist them, and sometimes women who are merciful come in to help. (male caregiver, 40 years)
>
> I believe there are male caregivers, you can't tell. What I know [is] when you have a patient, you have to give all the care he needs. If she is your wife and there is no other person, you have to care. (male caregiver, 52 years)

Regarding the type of care provided, responses indicated that it included the provision of material needs like food and clothing, hands-on care like washing, emotional support where caregivers pray with the patients, and transportation—taking them to the hospital when their condition worsens:

> I have been buying all the necessities, like sugar and other things and at times give him water. But other physical assistance has been offered by my wife. (male caregiver, 63 years)

Few respondents noted that there are situations where men provide care when women are around. Only one caregiver said that in situations where women have to carry on with other important tasks like digging, the men temporarily stand in for them. Some female respondents expressed frustration that women had to provide hands-on care tasks like washing and cooking, even when a man was available. It was rare that men took on the role of the principle caregiver when a woman was available:

> That is mainly caused by disunity in the family. Maybe a wife is not on good terms with the patient or the husband himself. (female caregiver, 46 years)

Generally, most responses indicated that women were expected to be the principle caregiver and were expected to do the majority of the care tasks. This also was echoed by the male caregivers, who mostly confirmed that they became the caregiver only because no woman was available for providing care. Even the women saw themselves as being in the "natural role" of the caregiver, and men doing the tasks when a woman was available widely was viewed as happening only in dysfunctional families.

Caregivers' Burden

The majority of the respondents said their productivity and income, emotional well-being, and physical health negatively were affected by their role as caregivers. This reportedly was associated with the length of time they have spent caring for the patient and the frequent bouts of illness they as caregivers had to endure as AIDS progressed. All caregivers said that the provision of care has had a negative impact on their well-being since caregiving began:

> Because of sleepless nights and the care needed by the patient, ... I am feeling weak. (female caregiver, 39 years)
>
> After starting to look after the sick, I am weak because I even lost the other two (AIDS patients). (female caregiver, 70 years)
>
> My income was greatly affected, I had a retail shop, but since I have started nursing her, it fluctuates due to the everyday demands and now I only depend on my husband's income. (female caregiver, 46 year)
>
> I have problems of lack of finances, cooking for the patient, and to be always on his side. (female caregiver, 43 years)
>
> If there weren't problems, I would have increased my income. I had children in school, but due to those problems, I stopped them from attending school. But sometimes I pay in halves when they accept up to the end of term. (male caregiver, 40 years)

In most households, where more caregiving tasks were shared, it was the children who had to carry out more household chores and had to participate directly in the care of the patients. This led the children to attend school irregularly or even to completely drop out in order to provide support to the patients and the family caregivers. Generally, it became absolutely clear in the responses from all caregivers that the burden the caregiver faces is very high and that the high burden had affected their health. One example was an elderly caregiver who contracted tuberculosis from her patient because she did not know that he suffered from it or how to protect herself from this infection. The fear of contracting a communicable disease from the patient, however, was not expressed in all in the interviews.

Caregivers' Coping Mechanisms

Responses indicated that the household members' financial status was a major factor in determining their ability to cope with the burden of care. Other factors to be considered included the position of the ill family member (breadwinner or dependent), available external sources of help by friends and relatives, and the nature of the household (female-headed or not).

Caregivers' responses to the question of how they cope with the burden of care were varied, including changing their patterns and work schedules, reallocating resources from other needs like children's education, and selling family assets. In some cases, particularly in widows' or female-headed households, the older children stopped going to school to provide additional labor as well as to reduce demands on the limited income in the household:

> The young ones are at school. When they come for holidays, they go to dig in the banana plantation. (female caregiver, 73 years)

In households where the patient was the main income earner, the caregivers reduced the time spent on their work to provide care for the patients and to raise income by selling off family assets to meet the patient's needs:

> I sold domestic animals and some land to look after my husband. (female caregiver, 19 years)
>
> I had a shop which has now become weak because of increased costs and less time for me to go and work. We now depend on my husband's income for survival. (female caregiver, 43 years)

One caregiver was a married woman who has nursed her husband for 3 years. The couple has three young children. Due to her husband's recurrent illness, she stopped her private business to provide adequate care for him:

> In the past I used to have some pottery work among others, but now I cannot because all the time (I) am here taking care of the patient. (female caregiver, 37 years)

To the question of how the caregivers think they can raise income to meet their increasing demands for care provision, respondents gave various suggestions, mainly focusing on initiating income-generating projects including animal husbandry, crop farming, and cottage industries like brick making and retail shops:

> If I had a project like brick making, I can sell the bricks. (male caregiver, 40 years)
>
> I put money in business like selling shoes and even retail shops. (female caregiver, 46 years)
>
> The form of assistance can be money to buy drugs, and the balance I start to rear goats for future plan. (male caregiver, 43 years)

Regarding the formation of organized community groups to carry out income-generating projects, respondents' general view was that income-generating activities in groups are not very successful:

> The problem with groups is that people are not cooperative, that is why they collapse. (female caregiver, 70 years)
>
> What we had was one for digging and . . . the whole exercise lacked transparency in terms of sharing. So we ended up getting losses and the whole process collapsed. (female caregiver, 73 years)

It was surprising to hear that the improvement of the financial situation was viewed by most as one major mechanism for coping. Although stating that their health has suffered due to caregiving responsibilities, no caregiver mentioned that the improvement of their dire personal situation (e.g., health) could be through direct health services provided to them (home-based care nurses provided care only for the patient) or through relief by a respite program. The description of their situation as a matter of fact and the fact that very few caregivers complained too much about their situation let us believe that Ugandan family caregivers provide loving and passionate care to their AIDS patients within their means of possibilities.

Caregivers' Knowledge and Skills in Care Provision

The knowledge or skills in care giving mainly were acquired by the caregivers themselves through learning on the job. Only a few respondents actually have attained training on patient care earlier when the home-based care was more functional and had provided special training for family caregivers in basic care provision. The lack of adequate skills for caregiving in the home was a general major concern for all participants, but it also became clear that caregivers were eager to learn:

> No, I do not have enough knowledge of how to care for the patient as this is my first time. (female caregiver, 39 years)
>
> I know the measures and kind of medical care to give the sick person.... I always go for seminars to learn more concerning where to go for assistance or to learn more about the disease. (female caregiver, 43 years)

Responses to the question on AIDS drugs (antiretroviral drugs) indicated that most of the caregivers had limited knowledge. Only one caregiver said her patient is receiving them. The majority said they have heard of expensive drugs that poor families cannot afford to buy, but they did not know more details about them:

> I know them; they assist in providing energy to the patient. She has been using them only of recent, because we had no money to buy the drugs from Buhinga hospital. They have really improved her condition, because she came when she was very ill but now there is a change. (female caregiver, 73 years)
>
> I hear... the medicines are not affordable by us the poor. So I do not know what plans you have for us. (female caregiver, 46 years)

A male caregiver who has been caring for his wife has two adult children who no longer live with them. Their youngest son comes to relieve his father by cleaning and washing the patient as well as providing funds for food and milk. When asked about his knowledge of HIV/AIDS drugs, he said,

> I hear that there are drugs and they are soon coming, probably next year, and will be stocked in hospitals. I will get them if I am still alive. (male caregiver, 60 years, with HIV infection)

The concern of caregivers not having enough knowledge and skills, thus not being able to provide the best care possible, was universally expressed. It also was clear from the responses that the caregivers were very keen to learn and would attend training offered to them in spite of their time constraints. Only one caregiver said that she attended a seminar on basic care.

Support for Caregivers

Respondents acknowledged having received assistance from neighbors and friends, which, however, was limited:

> It takes long because everyone has his or her own problems and it's hard and takes long to get assistance. (male caregiver, 40 years)

Most responses showed that friends and neighbors occasionally visit the affected households to comfort the caregivers and the patients as well as to express their sympathy. Only few respondents said that neighbors come more often. According to one respondent, this was important:

> Yes, neighbors and friends usually come to visit me and give me comfort. (female caregiver, 73 years)

In a few cases, respondents said friends and neighbors provide hands-on and material assistance. Much of the care, however, is still the responsibility of the immediate relatives who live with the person:

> There is her son (the patients')...who lives in Katooke and does some of the work like cleaning her. I myself do the cleaning, looking for medicines, washing clothes, and even cooking. (male caregiver, 60 years)
>
> I now do it myself, but when the father was still alive, he used to come and help me. When he died, I was left to do everything alone. (female caregiver, 46 years)

In some cases, the relatives did not offer any support even when they could afford it:

> The father is a rich trader, but he gives no assistance in any form. (male caregiver, 40 years)

Caregivers said the churches and church hospitals play an important role in care provision by giving emotional and spiritual support as well as treatment for the patients and their caregivers.

> The church (Protestants) come and pray for us. (female caregiver, 73 years)
>
> The assistance I got from the hospitals (church hospitals) and from the churches is in terms of prayers, drugs, and visits at any time. What I have received from them is what they can afford and I thank God for that. (male caregiver, 40 years)

All participants clearly expressed that they did receive little support from government or nongovernmental organizations. The only program with outreach to the homes was the home-based care program for AIDS patients run by the District Health Department, which was viewed as largely dysfunctional. This program has been funded by external sources that were discontinued recently. Therefore, only few of the participants received minimal support from this program, while most of the others said that they have not benefited at all from program activities in spite being on the client list.

In summary, we can say that the care burden for the principle family caregiver is very high as it entails having to cope with recurrent depressive situations of ill health, suffering, and death of loved ones. The family caregivers' responses indicate that much of the care is provided by immediate family members who are faced with the enormous task of giving physical and emotional support for their patients when they themselves need it. In contrast to that is the mere absence of support services and training opportunities for the caregiver and limited support by neighbors and friends.

DISCUSSION

The overall results from our study indicate that family caregivers of AIDS patients are overwhelmed with their responsibilities and bear a high burden due to the very poor conditions in rural Uganda. The high caregiver burden reported by our participants, with its negative impact on their health status, is in line with two other report from Uganda (Brouwer et al., 2000; MacNeil, 1996) and with reports from the other sub-Saharan African countries of Botswana, Kenya, and Zimbabwe (Lindsey et al., 2003; Olenja, 1999; Robson, 2000). It is interesting to note that Lindsey reported similar levels of family care problems for AIDS patients in Botswana as we did in Uganda. Botswana is a relatively rich country with a significantly higher gross domestic product (GDP) and where many more resources are available in families and within the government. The stigma of AIDS also is reported to be high in Botswana, while in Uganda the stigma was said to have decreased (Kipp, 2007). This led us to believe that economic factors alone cannot explain the burden of family caregivers, as our family caregivers said. Other factors such as family structure, family dynamics, and culture and gender roles have to be taken into account as well. Obviously, the HIV/AIDS epidemic has instigated changes in family roles and has resulted in situations that have challenged traditional family structures and eroded predictable patterns of behavior. This likely has added even more anxiety and stress for the caregiving families and the patients.

The coping mechanisms for HIV/AIDS-afflicted households included changing the work schedules and patterns by decreasing the time spent on other activities like gardening and retail trade. In some cases the older children stopped going to school in order to provide additional help at home. From the caregivers' responses, it is clear that coping mechanisms for households are determined by their economic status, social position of the ill member of the family (breadwinner or not) and the nature of household (female headed or not), as mentioned above.

Caregivers' situations are worsened by lack of adequate information about the HIV/AIDS epidemic, available medical treatment for the patients, and skills required for effective care provision. Although fewer male caregivers were interviewed, the lack of knowledge seems to be more evident among female caregivers, suggesting that they may have fewer opportunities to attend seminars and to listen to radio programs. The lack of information and basic skills in patient care exposes caregivers to dangers of contracting some of the infections from their patients. Responses indicate situations where they too fall ill as a result of caring for their ill relatives.

The lack of adequate information on the clinical aspects of HIV/AIDS within families also affects the way caregivers react to recurrent episodes of illness. Family caregivers often are frustrated and worried about the health of their patients and end up wasting productive time in sitting by the patients' bedside, because of a fear that they will die at any time. Therefore, caregivers' productive time is shifted toward (unnecessary) patient care at the expense of other vital household activities like food production, which leads to further economic hardship within the household.

According to the responses in this study, caregiving is still considered a female role within the households, ranging from the elderly grandmothers to young girls. The interviews indicated that men's involvement in care provision for AIDS patients arises in situations where there is no able female to take over the role. The increasing impact of the HIV/AIDS epidemic on the productive members of the community now obviously has shifted to older members of the family and grandparents and children, as the age distributions of our participants shows. The positive view of a few caregivers, however, was that men are now more willing to participate in patient care, which could shift some of the care burden and distribute it more equally within the family. This is encouraging and important to note, because this could be one option to reduce the care burden for female caregivers. This should be strongly encouraged by all formal health care workers involved in home visits.

The high burden of family caregiving results in work overloads and time constraints that give caregivers less opportunities to generate income and participate in social and developmental activities. This will have a strong negative effect in the long term on the development and healthy families, communities, and entire nations. This is a problem of huge magnitude and is, by and large a gender issue since the majority of caregivers are female.

RECOMMENDATIONS

An effective response to mitigate the impact of HIV/AIDS must include caregiver issues and strengthen the caregivers' capacity to meet the challenges of care through the following five recommendations:

(a) The resolution of HIV/AIDS programs to also include family caregivers as their legitimate clients in their HIV/AIDS policies and plans has been done in much of the developed world. We realize, however, that the most challenging aspect of a change of this magnitude is not the policy development per se or even the allocation of the resources required, but rather the shift in thinking that results in recognizing and serving families rather than individual patients.

(b) The need for training in counseling and basic nursing care skills for all family members, especially caregivers, cannot be overemphasized. This is critical given the level of awareness displayed in the interviews. Special consideration should be given to female caregivers whose household chores do not allow them time to attend the scheduled training workshops and seminars. Training should be organized in a realistic way so that caregivers can attend. Educating the caregivers at home would be the best option. If this has to happen, policies have to be changed and outreach workers have to be trained and sensitized toward considering caregivers as a target group.

(c) Focus must be on increasing the role of men/boys in care provision beyond what they are now doing. It is clear from this study that if men are trained, they are able to provide the needed care as well as their female counterparts. Increased efforts for men's involvement in care should be undertaken.

(d) The need to strengthen the role of faith-based institutions (churches) in their caring role is critical. Spiritual support was very important for our participants. More church outreach services to family caregivers would lessen their emotional burden. Providing care is considered one way of demonstrating spiritual faith.

CONCLUSION

Clearly there is an urgent need to recognize the severe impact of the HIV/AIDS epidemic on family caregivers who for the most part are female, including elderly women and young girls. In sub-Saharan Africa, females already were disadvantaged before the era of HIV/AIDS and now are further burdened by this epidemic. As always, where needs are so extensive, it is a question of determining priorities and sharing responsibility across sectors if any impact in alleviating this burden is to occur. All sectors must be asked to include support for this disadvantaged caregiver group of the population. The "hidden reality" has to be brought to the attention of all agencies, service sectors, and the public in order to create more awareness about their caregiver burden. This awareness is essential to the creation of support programs for family caregivers to alleviate some of their suffering.

Family caregivers' issues of AIDS patients in Uganda clearly are far beyond the problems that the health sector alone can resolve. Caregiver burden, as identified by our sample, is a heavy financial, economic family burden that health professionals cannot usually address. If a model could be implemented where the emotional support for family caregivers from church parishes could be strengthened, where the health sector could make antiretroviral drugs readily available, and where the social assistance services could compensate family caregivers with meaningful allowances (for example, as is done in Botswana), then perhaps major strides forward would be achieved even in the short term. Although discussions of caregiver issues are just beginning in sub-Saharan Africa, if we learn from the past, we will not allow endless discussions and other delay tactics to interfere with the progress possible in implementing family caregiver support programs.

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