How Much Should We Expect?
Family Caregiving of AIDS Patients in Rural Uganda

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The aim of this study was to measure the burden of care for family caregivers of AIDS patients. A cross-sectional exploratory design was used to describe the care experiences of family caregivers of AIDS care recipients. A questionnaire was used to interview 120 family caregivers of AIDS patients from four rural areas in western Uganda. The questions asked were related to 12 domains of family caregiving. Care burden scores of caregivers were calculated. It was found that care burden scores were high in all domains except those regarding relationships within the families and substance abuse. Serious work overload and low health status were reported. The high burden of caregiving puts family caregivers at risk for decreased health status and increased social isolation and depression.

Keywords: *Uganda; HIV/AIDS; family caregiver; care burden*

Little information is published about family caregiver burden that exists in sub-Saharan Africa because of the HIV/AIDS pandemic. The topic of medical and social support for family caregivers of AIDS care recipients in sub-Saharan Africa (how it is provided, by whom, and under what circumstances) has barely been covered in the international literature.

Although it is reasonable to assume that the extended families and the social safety nets in Africa have absorbed some of this burden, it is also reported that these safety nets are stretched to the limit by the enormous burden of caring for severely sick and dying AIDS care recipients in the home (Seeley, Kajura, & Bachengana, 1993). In Uganda, it was found that home care is not always feasible and that neighbors, when asked to help, often refused to help families requesting it (Ntozi, 1997; Seeley et al., 1993). Jackson and McDonnell stressed that professional home care services in Africa, if they exist at all, are often overwhelmed in the attempt to provide adequate services and that new approaches are needed (Jackson & Kerkhoven, 1995; McDonell, Brenna, & Burnham, 1994).

With the limitations of accessibility for both professional home-based care and hospital care, most often the burden of care for AIDS care recipients falls on the family members, especially on women, who in Africa are traditionally considered as the principal caregiver (MacNeil, 1996; Olenja, 1999). This poses enormous responsibilities and/or stresses primarily on women in a situation or society where women are already overburdened with their responsibilities for the general health of their families, for household food security, for their children's welfare and/or education, and for managing scarce resources. Furthermore, AIDS care recipients and their family caregivers live in communities where stigma surrounding HIV infection and clinical AIDS exists (Anderson, 1994; Kalondo, 1996). Stigma often leads to social isolation and loneliness not only for AIDS care recipients but also for their family caregivers at home and other family members (Casaux & Reboredo, 1998).

Other authors stress the importance of family caregiving, especially in poor rural settings where formal health care services are virtually absent (Chela, Campbell, & Siankanga, 1989; Reijer, 1999; Robson, 2000). However, few studies have addressed issues facing family caregivers for AIDS care

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recipients. Brouwer and MacNeil described the struggle and difficulties of Buganda women in Uganda of providing love and care for their relatives with AIDS (Brouwer, Lok, & Wolfers, 2000; MacNeil, 1996). Ndaba-Mbata and Seloilwe (2000) reported that family caregiving in Botswana was poor because family caregivers were not trained to provide basic care. Similarly, Olenja (1999) found that training in AIDS care was grossly lacking at the community and household level in Kenya and that family AIDS caregivers were worried about their lack of skills to care for their loved ones. In South Africa, it was found that family caregivers of children with AIDS had a huge knowledge gap in providing appropriate care (Zimba & McInerney, 2001). Brouwer et al. (2000) also observed that mothers in Uganda who care for their children with AIDS had a heavy emotional burden that prevented them from following the advice given to them by health care workers and thus from delivering proper care for their children. Robson (2000) described that young girls in Zimbabwe were disproportionately burdened with caregiving responsibilities for family members with AIDS, which negatively affected their education and career options.

To shed more light on family caregiving of AIDS care recipients in sub-Saharan Africa, we conducted a study in Kabarole District, western Uganda, to assess caregiving issues of AIDS care recipients who were cared for at home and to quantitatively measure the burden of care for the principal family caregiver, using a validated tool. The main research questions that were addressed through this study were the following:

1. How heavy is the burden of care for family caregivers of AIDS patients in Kabarole and Kamwenge Districts?
2. How much are family caregivers in Kabarole and Kamwenge Districts at risk of becoming ill and being "burned out"?
3. What are the family caregivers' needs for support, and what support services are available?

The broader study was conducted in the first quarter of 2003. It combined quantitative and qualitative research methodologies. Methodology and results from the qualitative part of the broader study are published elsewhere (Kipp, Tindyebwa, Rubaale, Karamagi, & Bajenja, in press). In this article, we report the results from the quantitative component of this study, using a structured interview-administered questionnaire.

During the time the study was conducted, highly active antiretroviral therapy (HAART) for AIDS was not available in the study areas. Kabarole and Kamwenge Districts have a home-based care program that consists of a formal and a family part. 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 family part of the program is composed of family members who are the principal caregivers for the AIDS care recipient at home. Our definition of the family caregiver refers to one family caregiver, who takes most of the care responsibility for an AIDS care recipient at home (which is usually the spouse, if available).

In the past few years, home visits of professional nurses have declined because of funding shortages of the Kabarole and Kamwenge Health Departments. The rural study areas are typical for sub-Saharan Africa, with a high burden of infectious diseases including malaria and tuberculosis. All homes visited during this study had no running water and no electricity, and most of them were of poor building quality.

METHOD

This cross-sectional, exploratory, quantitative study component was designed to describe the care experiences of family caregivers of AIDS care recipients. The respondents were family caregivers of AIDS care recipients and selected from four subcounties within Kabarole and Kamwenge Districts (Kaihura, Kibiito, Kahunge, and Kataraka).

Ethical Considerations

Ethical approval was given by the Health Research Ethics Board (Panel B) of the University of Alberta. The study was approved by the Uganda National Council for Science and Technology, Kampala, and by the District Officer of Health of Kabarole and Kamwenge Districts. In the four study sites, communal consent was obtained from the local chiefs and local council chairmen as elected representatives of the population. Each participant was provided with an information and consent letter. Each person who agreed to participate in the study signed the consent letter. Participants were interviewed at a location of their choice. No individual names were recorded.

Sampling Procedures

The primary sample of 120 caregivers was drawn from households included in the Kabarole and Kamwenge home-based care program. In each area, a systematic sample of AIDS care recipients from their active patient list was drawn. Nobody refused to participate. A questionnaire (the 12 questionnaire items are shown in Table 2) was applied with questions pertaining to domains (which have been identified in Canada and which were regarded as being important for the family caregiver burden) such as the profile of the caregiver, the profile of the care recipient, caregiving tasks, support for caregiving, housing, scope of caregiving responsibilities, personal health, family relationships, and crisis intervention. The interview lasted between 90 and 120 minutes.

Development of Data Collection Tools

The assessment tool used for this study comes from Gubermann, Keefe, Fancey, Nahmiash, and Barylak (2001), who developed a screening and assessment tool (questionnaire) for family caregiver burden that has been validated and used in Canada. The aim of creating this questionnaire in Canada was to develop an appropriate instrument for assessing and evaluating specific needs of family caregivers that takes into account their reality and conditions and that situates them as essential partners with the formal health care system in the care of dependent adults or children. This tool was found to have high construct validity, high internal consistency (Cronbach's alpha = .88), and high test–retest reliability.

The questionnaire was used by interviewers. It consisted of two parts: The first part of the questionnaire was developed to quantitatively measure the family care burden, whereas the second part was descriptive. The first part contained 21 questions. Nine questions were related to general information about the family caregiver such as age, sex, relationship with care recipient, health status of care recipient, and duration and intensity of care. The remaining 12 questions aimed at assessing the family caregiver's care burden and are outlined in Table 1. Responses to these burden questions were structured as Likert-type scales (*strongly agree*, *agree*, *disagree*, *strongly disagree*), which were later transformed into a score for each individual question (*strongly disagree* = 0, *disagree* = 1, *agree* = 2, *strongly agree* = 3). For each of the 12 questions in Table 2, a score was obtained ranging from 0 to 3 and presented as a mean score with a standard deviation as recommended by Guberman et al. (2001). The interpretation of the care burden score was made as follows: 0 = *no care burden*, 1 = *moderate care burden*, 2 = *high care burden*, 3 = *very high care burden*. For example, a mean score of 2.49 for Question 2, "I am not coping well," would indicate high to very high burden, that is, family caregiving has severely affected one's coping ability.

The descriptive part of the questionnaire consisted of several parts:

(a) caregiving work and support;
(b) caregiver's relationship to formal services;
(c) caregiver's ability to juggle responsibilities;
(d) caregiver's physical health;
(e) caregiver–care recipient relationship; and
(f) planning issues, crisis planning, and the future. Seventy-four structured questions were asked during this part of the interview.

The following five steps were taken to adjust the Canadian questionnaire to the conditions as they exist in western Uganda.

1. The Canadian concepts behind some of the 12 items in the Canadian questionnaire (first part) were checked for their existence in the local (Rutooro) culture. For example, concepts of physical health (Item 1), mental health (Item 10), social relationships (Item 3), and family relationships (Items 4 and 6) are well known in this local culture, and words in the local language Rutooro exist for all.
2. The questionnaire was modified to the Ugandan situation and pilot tested with five family caregivers who were not part of this study. The comprehension of the questions was found to be very good, with few changes required after the pretesting. For example, "physician visits" were replaced by "visits to a nurse," because nurses are the main providers of health services in Kabarole and Kamwenge Districts, and very few physicians are available. In addition, input from health officials and community leaders was sought to further adapt the questionnaire to the local context.
3. Internal consistency of the Ugandan responses to the questionnaire items (first part) was determined with a Crohnbach's alpha test. Whereas the internal consistency of the Canadian responses to the Canadian questionnaire version was high (Crohnbach's alpha = .87), the internal consistency of the Ugandan responses to the Ugandan version of the questionnaire by our study participants was found to be a Crohnbach's alpha of .67. Nunnaly and Bernstein (1994) stated that in the early stages of a research process, a modest reliability as measured by a Cronbach's alpha of .70 is sufficient. As Cronbach's alpha in our study was only slightly lower than that recommended, we conclude that the internal consistency of the Ugandan version of this questionnaire was high enough to measure the care burden in our family caregivers.
4. The linguistic reliability of the questionnaire was enhanced by using a highly qualified and experienced interpreter for the translation of the questionnaire from English into Rutooro and for the back translation from Rutooro into English. This was checked by the best expert (teacher) in both languages available in the area. If inconsistencies were detected, the phrasing of the questions was changed accordingly.
5. To minimize interview bias, highly qualified interviewers (one man interviewing male caregivers and one woman interviewing female caregivers) with long-standing experience in interview techniques conducted the interviews in the local language, Rutooro.

Data Analysis

The data were entered in Stata, version 9.0, and analyzed using descriptive analysis (Stata, 2005). Responses to the 12 domains of caregiving in Part 1 of the questionnaire were analyzed in two ways: (a) percentages for agreement and disagreement are given, and (b) care burden scores for the essential caregiving elements were calculated, tabulated, and interpreted using a scale from 0 to 3 (0 = *no care burden*, 1 = *moderate care burden*, 2 = *high care burden*, 3 = *very high care burden* according to the assessment model).

RESULTS

Caring for AIDS care recipients is still almost exclusively the role of women. Men are only taking responsibility for care if the situation at home is absolutely desperate, for example, no women in the family (or in the extended family) are available for caregiving responsibilities. In our sample of 120 caregivers, 29 (24%) were male, whereas 91 (76%) were female. If there was a need for girls to help with care and household chores, they were taken out of school. The

TABLE 1
Caregiving Tasks of Family Caregivers of AIDS Patients in Rural Uganda ($N = 120$)

Caregiver Task	*Number of Caregivers (%) Performing These tasks*
Occasional feeding[a]	97 (81)
Daily feeding	44 (37)
Call home-based care nurse	86 (72)
Give medication	70 (58)
Washing/bathing	67 (56)
Change position in bed	47 (39)
Occasional incontinence care[a]	46 (38)
Daily incontinence care	37 (31)
Help walking the patient	41 (34)
Dressing wounds	36 (30)
Physical exercise of bedridden patient	33 (23)

a. Occasional means two to three times per week.

age distribution of the caregivers was as follows: Mean age was 39.3 years (*SD* = 17.4 years) and ranged from 12 to 85 years. Eighteen (15%) were younger than 19 years, 38 (32%) were older than 50 years, and 6 (5%) were older than 69 years. This indicates that almost half of the caregivers are young or old. Only 8 (7%) participants cared for spouses, whereas the other care recipients were family members. However, 29 (24%) care recipients were distant relatives and members of the extended family. Most of the care took place in the homes, and very few caregivers (8%) reported providing care outside of their residence in another home. Mean length of caregiving was 4.5 months (*SD* = 6.8, range 1-23 months). An average of five children was living with the caregiver, and their welfare was also the caregiver's responsibility.

Most of the AIDS care recipients were in an advanced clinical stage of HIV/AIDS, and many required constant attention and care. Care recipients were mostly women (71%). Twenty-four (20%) were children. Seventeen (14%) care recipients were older than 50 years, and 6 (5%) were older than 60 years. Twenty-eight (23%) care recipients were living in a separate home, whereas the others lived with family members (5% with grandparents, 2% with nonrelatives) in the same household. Sixty-two (43%) family caregivers said that their patient had "bad behavior" such as drinking, smoking, and being aggressive toward them. Caregiver tasks are described in Table 1.

Forty-seven (39%) care recipients could not walk anymore. Four (3%) care recipients never had any medical care by a trained health worker despite being on a patient list for home visits. Forty-six (38%) caregivers reported that they were told by the home-based care nurse to provide physical exercise if their patient was bedridden but were never told or instructed how to do it. Most of the family caregivers had to perform all the household tasks such as cooking, shopping, washing, cleaning the house, and working in the garden as well. Eighty-eight (73%) family caregivers reported that they check on their patient every night.

Most family caregivers said that they need more help (54% nursing care, 21% transport, 22% financial, 3% feeding). One hundred six (88%) caregivers never had a break or respite in their caregiving responsibilities. Thirty-four (28%) said that they do not have any help in an emergency or crisis situation. Sixty-seven (56%) caregivers stated that caregiving is a full-time job (20% said it is a 24-hour job with little sleep), whereas only 16 (13%) said it is an occasional responsibility. Twenty-eight (23%) caregivers reported that they have to do paid work in addition to the caregiving to be able to support the family. All caregivers said that their economic situation has deteriorated since they became caregivers. Eighty-one (56%) said that simple medications such as aspirin are not affordable for them.

Most family caregivers rated their own health status as low (56% mental problems, 53% low physical health status). Eighty-two (68%) said that they had sleeping problems since they started caregiving. Other health problems cited were headaches, 62 (52%); backache, 60 (50%); tiredness 100 (83%); weight loss, 59 (49%); and exhaustion, 98 (82%). Emotional health was seriously affected by the enormous caregiving tasks in the following way: feel isolated, 92 (77%); feel sad, 108 (90%); are worried, 108 (90%); feel helpless, 106 (88%); feel overwhelmed, 83 (69%); and feel depressed, 110 (92%). Eighty-four (70%) also said that they are not able to find ways to relieve these feelings and talk to somebody about it. Seventy-nine (66%) said they had experienced a crisis situation in the past 4 weeks. For example, one caregiver said that her patient had to be admitted to the health center because of persisting nausea and vomiting with serious dehydration, and she had to run around to borrow money from friends and neighbors for transport to the health center and daily feeding. (Feeding is officially part of the government health care program in health centers, but often not available.) However, 106 (88%) caregivers said they still love their patients despite all the difficulties.

Only 14 (12%) family caregivers reported tension with the care recipients. Some of the reasons for the tensions were shouting, resisting care, and disagreements over decisions. Two (2%) caregivers reported that they were sexually abused by the care recipients, whereas 14 (12%) said that they were physically attacked by the patient. However, despite all the difficulties, 88 (73%) caregivers want to continue to provide the care required, but almost all (98%) want changes to occur to alleviate their care burden.

Results from the calculation of the care burden are presented in Table 2. Ratings are as follows: 0 = *no care burden*, 1= *moderate care burden*, 2 = *high care burden*, 3 = *very high care burden*.

The rankings in Table 2 of physical health as low, depression as very high, and coping abilities as very low indicate that the majority of the family caregivers are not

TABLE 2
Care Burden Scores of Family Caregivers of AIDS Patients in Rural Uganda (*N* = 120)[a]

Domain	Percentage Agreement[b]	Mean Score ± SD for Caregiver Burden in Uganda	Mean score ± SD for Caregiver Burden in Canada (for comparison)[c]
1. Care giving has negative effects on my health	64.4	1.87 ± 1.39	1.72 ± 1.16
2. I am not coping well	88.8	2.39 ± 0.89	1.41 ± 1.07
3. I am cut of from social activities	60.1	1.95 ± 1.22	1.82 ± 1.26
4. Caregiving has caused strain on my family relationship	22.4	0.66 ± 1.20	1.21 ± 1.24
5. I am unable to continue	47.7	1.23 ± 1.28	0.89 ± 1.10
6. Caregiving has caused strain on the relationship with my patient	17.8	0.49 ± 1.04	1.08 ± 1.20
7. Caregiving is no longer worth the effort	59.8	1.66 ± 1.31	0.37 ± 0.83
8. I don't have a minute break	40.2	1.26 ± 1.23	1.00 ± 1.12
9. I have more share of caring compared to others	83.2	2.45 ± 0.96	2.22 ± 1.16
10. I feel depressed	78.5	2.36 ± 1.10	1.21 ± 1.21
11. I am losing control of life	65.7	1.93 ± 1.25	0.87 ± 1.06
12. I increased intake of alcohol, cigarettes, medications	8.4	0.24 ± 0.81	0.43 ± 0.97

a. Likert-type scale: 0 = *no burden*; 1 = *moderate burden*; 2 = *high burden*; 3 = *very high burden.*
b. Agreement refers to a positive response including *agree* and *strongly agree.*
c. Canadian sample consisted of family caregivers in urban and rural areas of Quebec.

only at risk of suffering from ill health but are already experiencing health problems because of their high caregiver burden. (As they thought caregiving was the cause for their health problems.) The high ranking of "losing control of one's life" and "unable to continue" is indicating that the "burn-out syndrome" of Ugandan family caregivers is not uncommon. In Table 2, we also provide the results from a Canadian sample of family caregivers from the province of Quebec. These family caregivers were interviewed by Gubermann et al. (2001) with the same tool. Being fully aware that because of the extreme cultural differences, a more in-depth comparison is not valid, it was surprising to us to find that some rating patterns are quite similar in both samples, for example, high ratings were given to the items "Caregiving has negatively affected my health," "I am cut off from social activities," "I have more share of caring compared to others," and "I feel depressed" by caregivers in both the Ugandan and Canadian samples. On the other hand, ratings of items "Caregiving has caused strain on my family relationship," and "I increased intake of alcohol, cigarettes, medications" were lower in the Ugandan participants compared with the Canadian ones.

Caregivers expressed an overwhelming need for more support services. One hundred sixteen (97%) caregivers said that they urgently need help with the medical problems of the patients. Second important was direct financial assistance, which was requested by 71 (59%) participants. Training of caregivers by the home-based care nurse in the provision of good care was a serious issue and was requested by 49 (41%) participants, as those caregivers felt that they did not have sufficient knowledge to provide the best care possible. Respite care was asked for by only 46 (38%) caregivers, which seemed to be rather low (the concept of respite care is new and has not been introduced in the home-based care program in the study areas). Formal existing support services for family caregivers were not reported to exist at all. The most often cited source of family support was from church members, followed by neighbors and/or friends, and family members.

DISCUSSION

The international literature from developing countries indicates that little information is available and that the understanding of the care burden of family members for chronically ill patients is poor as our literature review has shown. Our study provides new knowledge about caregiver burden in Uganda and begins to enhance the understanding of family caregivers about their burden. We used a validated questionnaire for a family caregiving assessment that we adjusted to the local context, and we validated the results from the interviews with two focus group discussions that were part of the broader study (Kipp et al., in press). The use of very well-trained interviewers, pilot testing, and the validation of the data through qualitative assessments (which gave principally the same results as the questionnaire) gives us a high level of confidence that the results from our study are a valid reflection of the reality that family caregivers in Uganda face. Comparing our results to a similar Canadian study using the same tool showed that the burden of care for family caregivers in Uganda seems to be much higher, which would indicate a higher risk situation for them (e.g., scores for feeling depressed 2.36 vs. 1.21, scores for not coping well 2.39 vs. 1.41), bearing in mind that this comparison may be compromised because of the different social and cultural settings in both countries (Guberman et al., 2001). This summary measure was developed by Guberman and has been found to be very useful in North America. We, too, found it very helpful for our study.

Considering the clinical state of most patients (who were in the late stage of clinical AIDS), the nature of the care tasks required, and the conditions of most of the homes (having a thatched roof, no running water, no electricity, and no transport connections), caregiving was described by some caregivers as "intensive care in rural African huts." This intensity of the caregiving requirement is substantiated by a high number of caregivers (73%) who said that caregiving was a full-time job and by the fact that 56% said they had to get up regularly at night to help the patient. The level of caregiving burden we identified was reported to influence negatively the health of the caregivers, most of them being women, as 49 (68%) out of 72 women strongly agreed that caregiving tasks had negatively affected their general health. In addition, many family caregivers rated their physical and mental health low according to the results from the descriptive part of the questionnaire. They also related their low health to caregiving tasks, as they reported that their health deteriorated after caregiving has begun. Caregiving tasks therefore seem to contribute to women's ill health.

The age distributions of our study participants (with many being young or old) coincide with the maturity of the HIV/AIDS epidemic as it exists in Uganda. Obviously, the middle-age generation is not available for caregiving duties because of the high mortality in this age group (most likely because of HIV/AIDS). Therefore, this caregiving obligation falls either to the young or to the old, where the grandparents again take over child-raising responsibilities. The relatively high percentage of male caregivers (24% of all caregivers) indicates a situation where absolutely no women in the extended family can be found to care for an AIDS patient. It was interesting to find that 85 (71%) caregivers were women, because it is generally implied that women look after the men. This may reflect a situation in Uganda with a mature HIV/AIDS epidemic, where most men have already died and their HIV-infected female spouses were left behind and fell sick after their male spouse had passed away.

One study reports the tremendous personal suffering causing ill health experienced by caregivers for AIDS patients in North America that was mainly associated with the AIDS stigma (Powell-Cope & Brown, 1992). The association between caregiver burden and the health status of the (mostly female) caregiver was measured in one other study from the United States, where it was found that all women caregivers of AIDS patients were clinically depressed, and many were not supported by the existing services (Hackl, Somlai, & Kelly, 1997). One recent publication from Botswana reported a high burden of caregiving, especially for young girls (which was very common), who often missed school, were sexually abused, and exploited and depressed (Lindsey, Hirschfeld, & Tlou, 2003). In Malawi, it was found that caregivers were not prepared for their care tasks and that lack of basic care knowledge contributed to their care burden (Zimba & McInerney, 2001). Our study results fit well with the findings from these studies. We found, as the other studies did, a high psychological burden and low self-reported health status, which the participants themselves explained as being caused by their caregiving responsibilities. In addition, they reported desperation and a great physical demand for moving and lifting patients. Many family caregivers lacked knowledge to provide the best care possible for their patients.

To the best of our knowledge, our study of Ugandan family caregivers is the first to quantify the caregiver burden in sub-Saharan Africa. The high burden seems to be much higher when compared with a Canadian sample of caregivers. This comparison helps us to imagine how desperate the situation for many family caregivers of AIDS patients in Uganda must be.

Limitations

We recruited our participants from a caregiver's list from the home-based care program. Selecting patients using existing services may have caused selection bias. However, having selected participants who were in contact and aware of existing home-based care services and who generally may have been better off than those not using or not aware of these services let us believe that our study findings may have underreported the difficulties of providing care faced by our participants.

We did not validate the health status of those participants who reported that caregiving has had a negative effect on their health with other sources of information, for example, medical records. However, the self-reported health status has been shown in general to be strongly correlated with other "harder" physical measures of health status such as mortality, clinically diagnosed morbidity, symptom reporting, and health care utilization (Hoeyymans, Feskens, Kromhout, & van den Bos, 1997; Miilunpalo, Vuori, Oja, Pasanen, & Urponen, 1997).

Interview bias may have occurred. We tried to minimize it by selecting highly trained and experienced interviewers who were also well accepted in the community.

IMPLICATIONS FOR POLICY, CLINICAL PRACTICE, AND FUTURE RESEARCH

The high burden of caregiving puts family caregivers at risk for a low health status, increased social isolation, and depression. The work overload results in time constraints that give caregivers less opportunities to generate income and participate in social and developmental activities. This will have a strong long-term negative effect on the development and health of families, communities, and entire nations. This is a problem of huge magnitude and is by and large a gender issue because the majority of caregivers are women and young girls. Our study showed that family care is important for chronic illnesses in general, particularly for sub-Saharan Africa, where the provision of formal health care is very much limited.

The commonplace items that family caregivers in our study indicated would provide them significant relief are largely a matter of available resources. As always, where needs are so extensive, it is a question of determining priorities of needs and sharing the responsibilities to address the needs if any impact in alleviating this burden is to occur. Many health and social policies could be directed to alleviate the caregiver burden that has been quantified in this study.

We emphasize four basic policies as starting points in a change process that will be required to make a difference for family caregivers in Africa: (a) Funds available through gender-related programs from the international donor community should be targeted for female AIDS caregivers; (b) the conscious decision of local health and social services to target this caregiver population as a higher priority for their resources would result in specific indicators for resource deployment; (c) HIV/AIDS programs would also include family caregivers as their legitimate clients, which has been done in much of the developed world; (d) HIV/AIDS programs would provide antiretroviral drugs to all AIDS care recipients. These policies would lead to changes in clinical practice, because there would be resources available to assess both the clients and the family caregivers and to plan interventions to meet the needs of both.

Further research opportunities from this study are the following: (a) Use the study results as a baseline assessment to verify the impact of highly active antiretroviral therapy (HAART) on the caregiver burden (HAART was introduced in the study areas later), and (b) measure the impact of interventions for family caregivers in sustaining their valuable part of the care continuum.

CONCLUSION

The AIDS epidemic has brought the limitation of available services into the limelight again and heightened the need for support to family caregivers as essential to the continuum of care. However, the most challenging aspect of this magnitude of change 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.

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