

Family Caregiving to AIDS patients: The Role of Gender in Caregiver Burden in Uganda

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Abstract

The objectives of the study were: 1) What is the burden of care for male and female family caregivers of AIDS patients? and 2) Which factors influence the family care burden for AIDS patients at home? A questionnaire was completed by 29 male and 91 female family caregivers of AIDS patients living in four rural areas in western Uganda. Participating caregivers were selected from a patient list of the home-based care program for AIDS patients and then interviewed. The responses from the questionnaire were used to calculate care burden scores for caregivers of both genders and the scores in each group were compared. In addition, other factors relevant to the burden of family care were extracted and tested in bivariate and multivariate analysis to test whether they were predictors of the care burden. Results show that the care burden scores were high in all domains, except those regarding relationship within the families and substance abuse. Both male and female caregivers reported a similar care burden. Caregivers for spouses had higher care burden scores compared to those who cared for other relatives. The intensity of care was also a significant predictor of the care burden, while other factors

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such as age, duration of care, and cognitive function of the care recipient were not associated with the care burden score. The high burden of caregiving puts family caregivers at risk for a lower health status, social isolation and depression. As both male and female caregivers report similar care burden scores for the same responsibilities, men are not unduly overburdened with the family care of AIDS patients compared to women *and should be more actively involved in the caregiving process at home.*

Keywords: HIV/AIDS, family caregiving, gender roles

Introduction⁵

For many rural AIDS patients in sub-Saharan Africa, hospital care is not always affordable or accessible and home-based care services rarely exist. Therefore, most often the care for AIDS patients falls on family members, especially on women (McNeil, 1996; Olenja, 1999). This poses enormous responsibilities/stresses primarily on women in a situation/society where women are already overburdened with their other responsibilities for the general health of their families, for household food security, for their children's welfare/education, and for managing scarce resources. In sub-Saharan Africa, women are traditionally considered as caregivers in the families if a family member falls sick (McNeil, 1996). Furthermore, if a family member has AIDS, the family caregiver has to deal with the burden related to a chronic and deadly illness in the family and also with the stigma surrounding it. AIDS patients and their family caregivers live in communities where stigma surrounding HIV infection and clinical AIDS widely exists (Kalondo, 1996; Anderson, 1994). Stigma often leads to social isolation and loneliness not only for AIDS patients, but also for their family caregivers and other family members. This increases further their stress caused by caring for a loved one with a chronic and lethal condition such as AIDS (Casaux & Reboledo, 1998).

Women are most likely to become the principal family caregivers of chronically ill spouses or family members. Therefore, it is not surprising that studies in family caregiving have been primarily directed at women (Bull, 1990; Howard, 1994; Greenberg, Seltzer & Greenley, 1993). This is even more so for sub-Saharan Africa, where family caregiving is traditionally considered a role exclusively reserved for women. With the dramatic spread of HIV/AIDS, family caregiving has reached new levels in desperate attempts to try to provide the care required by many AIDS patients. Family caregiving occurs under extreme limited conditions in the home and where there is very limited access to the formal health care system. In some African countries, where HIV/AIDS began early (e.g. eastern Africa), many women who were family caregivers of an AIDS patient have died of AIDS. This has led to a situation, where women are not so readily available, even in the extended family, to be caregiver and men have to take over these caregiving responsibilities for sick family members. Indeed, one study from Uganda showed that out of 120 family caregivers of AIDS patients interviewed, 29 were males. It was also revealed in the above study that males did not volunteer to become a

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caregiver, but that they had no choice because females were not available (Kipp, Tindyebwa, Karamagi & Rubaale, 2006). The involvement of males in family caregiving is much more described in the literature from developed countries. The literature from developed countries reports that issues surrounding the involvement of males as principle caregivers of chronic sick family members has not been adequately addressed (Delgado & Tennstedt, 1997). We could not find any published article about males as caregivers of chronically ill family members from Africa, including how they cope with the stresses of caregiving, and how they perform their caregiving tasks. Generally, few published articles are available about issues surrounding family caregiving in sub-Saharan Africa (Sarason J, Pierce & Sarason B, 1994).

In a Canadian study interviewing male and female family caregivers, it was found that female caregivers had a 2.6 times higher odds for having a higher burden of caregiving. The same applied for depressive symptoms which were more likely to occur in female than in male caregivers (Gallicchio, Siddiqi, Langenberg & Baumgarten, 2002). In another study from North America, the health related symptoms reported by male caregivers caring for Alzheimer's patients were fewer than expected. Caregiver's health was related to perceptions of stress surrounding the provision of activities of daily living assistance. Most caregivers reported some level of depression (Shanks-McElroy & Strobino, 2001). From studies done in the United States and the United Kingdom, it was revealed that female family caregivers reported higher levels of care burden than male caregivers (Kramer & Kipnis, 1995; Morris R, Woods, Davies & Morris L, 1991). In a meta-analysis of 14 descriptive studies of gender differences in family caregiver burden, Miller et al. concluded that there were essentially no significant gender differences in the caregiver behavior when variables such as functional impairment of the care recipient, total caregiver involvement, or money management tasks were taken into account. However, female caregivers were more likely to report a higher care burden. The authors generally concluded that gender does not to play a big role in the delivery of family care and that more research is required on how gender-role explanations play out in understanding the caregiver behavior and burden (Miller & Cafasso, 1992).

Most of the studies reviewed here indicate that the caregiver burden for family members caring for chronically ill family members is not higher for male caregivers compared to female caregivers. In contrast, women generally are more likely to report a higher caregiver burden than men. This is important to note, because the active involvement of more males in family caregiving responsibilities would relieve women from some of their disproportionately higher share of caregiving tasks in two ways: First males would participate in caregiving together female caregivers to share the responsibilities for one patient. Secondly, more males would take on the caregiving role in lieu of a female caregiver. This relief is especially needed in the situation of female caregivers from countries in sub-Saharan Africa, where women traditionally have to assume the role of principal family caregiver. Making the involvement of men in the care of sick family members more culturally acceptable could substantially alleviate some of the women's high work load and free their time for other essential family health tasks such as caring for young children.

In order to shed more light on family caregiving and gender roles in sub-Saharan Africa, we conducted a study in Kabarole district, western Uganda to assess caregiving issues in homes where AIDS patients were cared for, and to measure the caregiving

burden of the principle family caregiver. Our definition of caregiver burden, used in this study, is broad and follows suggestions from Hoffmann and Mitchell, who state, that the imbalance between physical and mental resources to care for the patient and those available in the family unit constitutes the care burden. They conclude that the characteristic of the caregiving situation and availability of resources, rather than the condition of the care recipient, has a direct relationship to the well-being of the caregiver (Hoffmann & Mitchell, 1998). In our study we use this understanding of family caregiving burden which includes elements such as physical demands of caregiving, change in the social life of a caregiver due to caregiving activities, strain of caregiving on interpersonal relationships, the impact of caregiving on the well-being of the caregiver, the condition of the care recipient and to what extent the caregiver has exhausted his/her resources.

The two research questions which we addressed through this study were:

1. What is the burden of care for male and female family caregivers of AIDS patients in Kabarole district, Uganda?
2. Which factors influence the family care burden for AIDS patients at home?

The study was conducted in the first quarter of 2003. It was part of a larger study using quantitative and qualitative research methods to comprehensively assess the situation of family caregivers and the care recipients, who were all AIDS patients in an advanced stage in western Uganda. During this time, Highly Active Antiretroviral Therapy (HAART) for AIDS was not available in the study areas. Kabarole district has a home-based care program which consists of both formal services and family caregiving. The formal program is made up of professional, government paid nurses who are based at the nearest health centre and who visit the homes of patients who have been admitted to the program. The family caregiving component is comprised of family members who are the principle caregivers for the AIDS patients. In the past few years, home visits of professional nurses have declined due to funding shortages of the Kabarole Health Department. The rural study areas selected are typical for sub-Saharan Africa with a high burden of infectious diseases including malaria and tuberculosis. All homes visited during this study had few amenities with no running water and no electricity. The HIV prevalence varied from 5% to 15% of the sexually active population in the four study areas.

Methodology

This cross-sectional, exploratory, quantitative part of the research project was designed to describe the care burden of family caregivers of AIDS patients with special considerations of gender differences. The majority of respondents were rural family caregivers of AIDS patients from four areas within Kabarole district (Kaihura, Kibiito, Kahunge, Kataraka).

The primary caregiver was self-identified as the person who was most responsible for the day to day responsibilities for providing the care to the AIDS patient. All primary family caregivers also received some help from formal caregivers through the home-based care program nurses, as this sample was drawn from a client list of home-based

care for AIDS patients. None of the primary family caregivers included were paid by any source.

A sample of 120 family caregivers was drawn from households included in the Kabarole home-based care program. In each area, the first 30 patients on their active patient lists were selected. None refused to participate. A questionnaire was applied with questions pertaining to domains (which have been identified in Canada and which were regarded as being important for family caregiver burden) of caregiving. The interview lasted on average 30-40 minutes and was conducted in the local language of Rutooro. Participants were paid two C\$ for transport costs.

Development of data collection tools

The assessment model used for this study comes from Gubermann et al., who developed a screening and assessment tool for family caregiver burden, which has been used and validated in Canada (Guberman, Keefe, Fancey, Nahmiash & Barylak, 2001). This tool was found to have high construct validity, high internal consistency (Cronbach's alpha 0.88), and high test-re-test reliability. The aim of developing this tool in Canada was to develop appropriate instruments for assessing and evaluating specific needs of family caregivers which take into account their reality and conditions and which situate them as essential partners with the formal health care system in the care of dependent adults or children.

The questionnaire consisted of 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, 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 Lickert scales (strongly agree, agree, disagree, strongly disagree) which were later transformed into a score for each individual question (strongly agree=0, agree=1, disagree=2, strongly disagree=3). A total care burden score was obtained by adding the individual scores. The interpretation of the care burden score is as follows: 0=no care burden, 1=moderate care burden, 2=high care burden, 3=very high care burden. Scores for the individual questions could range from 0 to 3 and the total care burden score could range from 0-36.

Special considerations were given to adjust the Canadian questionnaire to the conditions as they exist in western Uganda. The following steps were taken:

1. The Canadian concepts behind some of the 12 items in the Canadian questionnaire 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 (item 4,6) 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 pre-testing. 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 was determined with Cronbach's alpha test. While the internal consistency of the

Canadian responses to the Canadian questionnaire version was high (Cronbach's alpha 0.87), the internal consistency of the Ugandan responses to the Ugandan version of the questionnaire by our study participants was found to be a Cronbach's alpha of 0.67. Nunnally and Bernstein stated in 1994, that in the early stages of a research process a modest reliability as measured by Cronbach's alpha of 0.70 is sufficient (Nunnally & Bernstein, 1994). 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. Highly qualified interviewers (one male and one female) with longstanding experience in interview techniques were used to conduct the interviews in the local language Rutooro in order to minimize interview bias.

Quantitative data were entered in Stata, version 9.0 and analyzed, using descriptive analysis (Stata Corporation, 2005). Care burden scores for the essential caregiving elements were calculated, tabulated and interpreted using a scale from 0 (no care burden) to 3 (very high care burden) as outlined above. Bivariate analysis was done with the two-tailed t-test if variables were normally distributed and with the Mann-Whitney two sample statistic if data were not normally distributed. Bivariate associations were tested with linear regression under the assumptions for the validity for this method. A multivariate linear regression model was developed with the total care burden score as the dependent variable and gender as the main covariate of interest. The other covariates entered in the model are shown in Table 3. The model also tried to identify other factors associated with the care burden score for family caregiving. A forward elimination process was applied to identify significant relationships and arrive at the final multivariate model. The significance level was chosen at 0.05.

Ethical considerations

Ethical approval was given by the Health Research Ethics Board of the University of Alberta. In Uganda, the study was approved by the National Council for Science and Technology and by the District Director for Health Services of Kabarole district. 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.

Results

In our sample of 120 caregivers, 29(24%) were male, while 91(76%) were female. The mean age of all caregivers was 39.3 years (SD 17.4 years) and ranged from 12-85 years. The mean age for male caregivers was 36.7 years and for female caregivers it was

40.5 years ($t=1.08$, $p=0.282$). Eighteen caregivers (15%) were below 19 years, 38 (32%) were above 50 years, and six (5%) were above 69 years. This indicates that almost half of the caregivers were either young or old. Only eight (7%) participants cared for spouses, while the other care recipients (CRs) were family members. However, 29 (24%) CRs were 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).

Care recipients were mostly females (71%). Twenty four (20%) were children. Seventeen (14%) CRs were over 50 years, and six (5%) were over 60 years. Twenty eight (23%) CRs were living in a separate home, while the others lived with family members (5% with grand parents, 2% with non-relatives) in the same household. Thirty one (29%) CRs were reported to be cognitively impaired.

Individual family care burden scores related to each of the 12 care burden questions are displayed in Table 1 with family care burden scores for males and females shown separately (see Table 1), as well as totaled.

Table 1: Family care burden scores of male and female caregivers in Uganda, n=120

Item	Average care burden score (median, interquartile range), n=120	Male (n=29)	Female (n=91)	P value
1. Care giving causes negative effects on my physical health	1.87 3 (0-3)	1.66 2 (0-3)	1.97 3 (0-3)	0.197
2. I am not coping well	2.39 3 (2-3)	2.20 3 (2-3)	2.35 3 (2-3)	0.505
3. I am cut of from social activities	1.95 2 (1-3)	2.11 3 (1-3)	1.88 2 (0-3)	0.347
4. I feel strain on family relationship	0.66 0 (0-1)	0.69 0 (0-1)	0.65 0 (0-1)	0.821
5. I am unable to continue caring for much longer	1.23 1 (0-2)	1.17 1 (0-2)	1.26 1 (0-3)	0.672
6. I feel strain on the relationship with my patient	0.49 0 (0-1)	0.34 0 (0-0)	0.56 0 (0-0)	0.360
7. Care is no longer worth the effort	1.66 2 (0-3)	1.48 2 (0-3)	1.76 2 (0-3)	0.310
8. I don't have a minute break	1.26 1 (0-3)	1.14 1 (0-2)	1.32 1 (0-3)	0.445
9. I have more share of caring compared to other family members	2.45 3 (2-3)	2.43 3 (2-3)	2.46 3 (2-3)	0.708
10. I feel depressed	2.36 3 (2-3)	2.06 3 (0-3)	2.50 3 (2-3)	0.105
11. I lose control of life	1.93 3 (1-3)	1.86 3 (0-3)	1.97 3 (1-3)	0.770
12. I consume more alcohol,	0.24	0.40	0.17	0.136

cigarettes, and medications	0 (0-1)	0 (0-0)	0 (0-0)	
Total score	18.49** 18 (15-22)	17.89** 18 (14-22)	18.80** 18 (15-22)	0.660***

* Score scale: 0=no burden, 1=moderate burden, 2=high burden, 3=very high burden, ** mean

*** two-tailed t-test, all other tests Mann Whitney two sample statistic

Overall, most of the scores for the individual questions as well as the total care burden score were lower for male caregivers except for the question “I am cut from social activities” and “I have increased my consumptions of alcohol and cigarettes” for which the scores were higher for males. All these differences were not significant.

Results from bivariate analysis with the total score for the family care burden as the dependent variable and the other characteristics of caregivers and care recipients as the covariates are shown in Table 2:

Table 2: Results from bivariate analysis with the total self-reported family care burden score as the dependent variable (n=120)

Variable	Total care burden score	Type of test	Test results		P value
Age		Linear regression	$\beta=0.025$	SE=0.034*	0.469
Sex	Male=17.9 Female=18.8	t-test	T=0.714		0.477
Relationship with caregiver	Direct family member=19.5 Relative=15.9	t-test	T=-2.842		0.005
Duration of care		Linear regression	$\beta=-0.022$	SE=0.017*	0.203
Live with care recipient in same house	Yes=18.5 No=15.1	t-test	T=-1.502		0.136
Care recipient cognitively impaired	No=18.8 Yes =17.6	t-test	T=-0.913		0.363
Intensity of care	All the time=19.6 Not all the time=14.4	t-test	T=3.796		<0.001

* Standard error

A positive association was found between the family care burden and the intensity of care. In addition, the care burden was higher if the care recipient was a close family

member (e.g. spouse, son/daughter) compared to a more distant relative (aunt, cousin, etc.). A gender difference in the care burden was not detected in this sample.

Similar results were obtained from a linear multivariate model with the burden score as the dependent variable (see Table 3).

Table 3: Results from the multivariate liner regression model with the total score for the family care burden as the dependent variable (n=120)

Variable	β coefficient	Standard error	P value
Intensity of care (all the time vs intermittent)	5.333	1.577	0.001
Relationship between CG* and CR** (direct family member vs relative)	3.161	1.258	0.014
CG lives with CR in same home (yes vs no)	0.835	2.593	0.748
Duration of care (months)	0.022	0.017	0.205
CR cognitive impaired (yes vs no)	-0.602	1.252	0.632
Age (years)	0.029	0.032	0.471
Sex (male vs female)	-0.585	1.214	0.631

* caregiver ** care recipient

As in the bivariate analysis, the intensity of care and the relationship of the caregiver to the care recipient were associated with the care burden. The constant in the multivariate model was 17.8, which refers to the average care burden score. The prediction of the care burden with this model could also be displayed as:

Family care burden = 17.8 + 5.3 for higher intensity of care + 3.1 for spouse. Surprisingly, the care burden score was not related to the duration of care and to the cognitive status of the patient.

Discussion

We used a validated Canadian assessment tool for family caregiving which we adjusted to the local context of the study area. The internal consistency of the responses in the Ugandan version of this questionnaire by the Ugandan family caregivers was sufficient with a Cronbach's alpha of 0.67 for this pilot study situation. 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 in which the care was provided (having thatched roof, no running water, no electricity and no transport connections), caregiving was an appalling task with many obstacles to overcome every day.

Our study results, showing no statistically significant difference in the family care burden for male and female caregivers are in line with a number of other studies mentioned before, especially with Miller who concluded in their meta-analysis of a series of papers the same result (Miller & Cafasso, 1992). In addition, several other authors also

found no significant differences between male and female caregivers in terms of burden scores, depression scores, or psychiatric symptom scores which included depression (Brodaty & Hadzi-Pavlovic, 1990; Neundorfer, 1991; Parks & Pilisuk, 1991; Shields, 1992; Hinrichsen & Niederehe, 1994). However, in many of the studies from developed countries reviewed, the care recipients were psychiatric patients, while our patients were AIDS patients in a late stage of the HIV disease and only 35 (29%) of care recipients were identified as being cognitively impaired. Additionally, in most studies from developed countries the care recipients were mostly elderly persons while in our study most care recipients were in the younger and middle age group. HIV/AIDS mainly affects the population between 15 to 45 years. Therefore, the comparison of our study with these studies has to be done with some caution because of the different nature of the medical condition of the care recipient.

Our analysis identified the intensity of care as well as the relationship of the caregiver with the care recipient as significant contributing factors to the family care burden score. Different care burden scores have also been found by Gallicchio and others depending on who the care recipient was (Gallicchio et al., 2002). Burden scores were highest when the spouse was the care recipient, followed by a child and lowest when other relatives were care recipients. Several other studies have found that spouses are more distressed than other relatives when caring for a family member (Brodaty & Hadzi-Pavlovic, 1990; Baumgarten, Battista & Infante-Richard, 1992; Grafstrom, Fratiglioni, Sandman & Winblad, 1992; Mays & Lund, 1999). Gallicchio and others conclude that the observation of higher care burden scores for spouses compared to other relatives must consider caregiving as an obligatory family responsibility for spouses which causes a higher care burden for them (Gallicchio et al., 2002). These findings may imply that respite services for family caregivers may need to differ depending on the relationship between the caregiver and the care recipient. This is also true for the situation of caregivers in our study, as family relationships are very important in the lives of Ugandans. The strong bonds between family members in our sample is demonstrated by the reply score to the question “I feel strain on the relationship with my patient” which was much lower compared to the results from a Canadian study, using the same tool (0.5 vs 1.0). We were not surprised to find that the stronger the emotional tie in between the caregiver and care recipient, the higher the care burden was.

The association between the intensity of care and the care burden was expected. In our study we did not measure the time input into the care tasks, as most other studies did not. The crude measure of the intensity of care as “always” and “intermittent” may not reflect the true situation and has its limitations. However, it is noteworthy, that all those respondents who said that they care all the time also said that they frequently have to get up at night to help the patient. There was no gender difference in the responses to the question referring to the intensity of care, as equal proportions of male and female caregivers said that they have to care for their patients all the time. This somewhat agrees with one study from Puerto Rico, where the time input for care was assessed and where it was found that sons and daughters put in the same time into the care process (Sarason J, Pierce & Sarason B, 1994). In our sample, duration of care did not contribute to an elevated care burden. This is consistent with observations from a US-based study, where men caring for mentally incapacitated patients did not express higher level of care burden

when they had cared for a longer time (Grafstrom, Fratiglioni, Sandman & Winblad, 1992).

Cultural values as predictors of caregiver behavior is emphasized by Zhan, who describes how Chinese caregivers are influenced by the Confucian norm, where obedience, provision and care towards the parents and/or other close relatives has always been emphasized (Zhan, 2004). In Uganda, the family structures are hierarchical with the head of the household being the dominant person. Responsibilities towards the family have the highest priority and precede loyalty towards other parties such as employers, neighbors and friends. How African/Ugandan cultural norms which are very different from North American norms influence caregiver behavior has to be examined further. We feel that our questionnaire measured accurately caregivers' behavior and care burden because we did an intense pre-testing and received input from local experts and community members. However, our interpretation of the responses from the Ugandan participants may have to be considered with some caution. Other limitations of our study were: 1) We could not randomly select participants because of ethical considerations. Selecting patients of a home-based care program may have caused selection bias. However, having selected participants who were in contact and aware of existing home-based care services and who generally are better off than those not using or not aware of these services, let us believe that our study findings may have under-reported the difficulties of providing care faced by our participants; 2) A gender-based difference in the response to the questions may have existed, e.g. men may be less likely to express their problems than women, thus resulting in an under-reporting of the care burden in men; 3) There may have been a "survivor" effect, as many AIDS patients and their (HIV infected) caregivers have died, which, as selection bias, limits also the generalizability our study results; and 4) The power of a study with 120 participants is somewhat low. An existing true difference in the family care burden score between male and female caregivers may not have been detected by this study. Therefore, the conclusion of no difference in the care burden scores between male and female carers has to be viewed with some caution. A study with a larger sample size and more a representative sampling method is required to confirm this lack of difference which we found.

Conclusions

The study's importance lies in the provision of caregiver information from parts of the world, where very little is known about it. The high care burden and its negative impact on the caregiver's health is an urgent problem which has to be addressed. Based on the latest HIV prevalence figures of the Ugandan Ministry of Health, an estimated number of 120,000 family caregivers exist in this country. As most caregivers are women, it represents also a women's issue of huge magnitude. A similar care burden of male and female caregivers does not mean that both put equal time into the family care process and provide equal quality of care to the patient (the quality of care by both groups should be measured by another study). It means that the involvement of men in the care process for sick family members *seems not to* unduly burden them as compared to female caregivers. If men would have significantly higher care burden scores than women for the same responsibilities, than it would be ethically more problematic to suggest more involvement of men in the care of severely ill family members. However, this is not the case.

Therefore, the greater male involvement in family caregiving could substantially reduce the current burden on women and could be achieved if some men recognized they too have responsibilities in family caregiving. Currently men merely assume this responsibility by default when no women are available, as we observed in our study. This sense of shared responsibility by both genders could slowly but surely help to change the culture of caregiving in Uganda. In addition, community support is urgently required for family caregivers both male and female. Support could result in such programs as respite care, home help, relief funds for disastrous financial family situations, and the creation of support groups for the caregivers. Government and community support for the family caregivers of AIDS patients needs to be strengthened. Family caregiving for AIDS patients must become an integral part of HIV/AIDS program planning and planners must start to consider family caregivers as legitimate beneficiaries of health funding. This is still not the reality in most sub-Saharan African countries including Uganda. Unfortunately, there are not many models from the developed world to guide a change in resourcing family caregivers, since this paradigm shift is not yet realized in the developed world. Perhaps the HIV/AIDS reality in the developing countries will be able to teach our world the long term gain of supporting family caregivers so that family capacity in society is more valued and hence appropriately supported.

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