Transitions in caregiving and health dynamics of caregivers for people with AIDS: A prospective study of caregivers in Nairobi slums, Kenya

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Abstract

Objectives: A cohort of older people living in a low-resource setting in Nairobi is followed to understand the transitions in caregiving status and trajectories in health over a three-year period. **Methods:** Three categories of older people comprising 65 AIDS caregivers, 102 Other caregivers and 1,322 non-caregivers identified at baseline were assessed at end-line based on two self-reported health outcome measures, a functionality score and having a severe health problem. **Results:** A majority of caregivers were still providing care at the end of the study, and or had taken on new care recipients. Compared with non-caregivers, AIDS caregivers reported poor health, with men more likely to report poor health than women. New caregivers also reported poorer health compared with non-caregivers. **Discussion:** The results indicate improvement in health over time among male caregivers supporting the *adaptation* model. We recommend timely programmes to support caregivers particularly at the onset of caregiving.

Key words: sub-Saharan Africa; caregiving impact; HIV programmes

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Introduction

HIV and AIDS affects older people through various ways and one indirect pathway occurs when older people become caregivers to people with AIDS or to orphaned children. Care-giving to people with AIDS has physical, emotional, financial and health consequences on the caregiver, similarly to most debilitating conditions (Knodel, VanLandingham, Saengtienchai, & Im-em, 2001; Dayton & Ainsworth, 2004). Within the family, older people play a key role in caring for people with AIDS. They assume the role as a filial obligation given that they are mostly parents to the ailing person. Conversely, older people act and perform this responsibility as heads of households or families and as a normative practice, as is common among societies in Africa and Asia (Ntozi & Nakayiwa, 1999; Knodel *et al.*, 2001). Men and older men in particular have received relatively little attention in studies on informal caregivers with older women featuring as central in the care and support for people living with HIV and AIDS to the extent of the epidemic labelled as a “grandmothers’ disease” (Wilson & Adamchak, 2001). Nonetheless, older men are instrumental in the care and support of people affected by HIV as evident in recent studies (Wangui, 2009; Boon et al., 2010; Kuo & Operario, 2011).

Important, albeit small, a number of studies have investigated the effects of caregiving to people with AIDS on the wellbeing of older people (Dayton & Ainsworth, 2004; Ice, Yogo, Heh, & Juma, 2010). The approach used to recruit participants varies from recruitment through medical clinics or organizations for people with HIV and AIDS for example (Knodel *et al.*, 2001), with a few selecting participants using stratified random sampling (Nyambedha, Wandibba, & Aagaard-Hansen, 2003). One limitation is the cross-sectional nature of these studies, and thus the inability to disentangle the effects of caregiving over time. This paper seeks to add to the literature that investigates long-term effects of caregiving on the health of older people providing care to people with AIDS using a case study of older people living in the slum areas of Nairobi, Kenya. The trajectories of caregiving status and changes in health over a 3-year period are examined by comparing various groups of caregivers and non-caregivers.

Effects of caregiving on health

The nature and intensity of care for people with AIDS vary according to the stage of the illness. During the extreme debilitating stage, a person with AIDS requires more care especially with basic routine needs such as feeding, bathing, laundry, use of toilet, and dressing. Forms of care relating to the health needs of the person with AIDS include administering medication, and seeking healthcare. Moral and emotional support also forms an important part of the care (Saengtienchai & Knodel, 2001).

Care-giving can endanger the health of the caregiver (Vitaliano, Zhang, & Scanlan, 2003). The extent of psychological and health impact on the caregiver may vary depending on the chronic ailments of the care recipient (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001). Caring for someone with AIDS is associated with complications which include the multiplicity of infections faced by AIDS patients and the stigma attached to HIV and AIDS (Grant & De Cock, 2001). This may compound the negative consequences associated with caring for someone with AIDS (Piot & Collseck, 2001). The intervening effect of gender on how caregiving impacts health has been noted but with mixed findings. Most studies highlight higher levels of burden and hence poor health outcome among women caregivers compared with men particularly in self-reported health outcomes comparing men and women. However, the gender differences may be a research artefact with men under-reporting symptoms, caregiver strain or distress (Kramer, 2002). The under-reporting by men could arise from the way men are socialised not to show fear or distress but be stoic and in control when faced with challenges. Nonetheless, this masculine persona does not imply that men are not negatively impacted by caregiving similarly or worse than women (Stoller, 2002; Kim, Loscalzo, Wellisch, & Spillers, 2006). Further, there are gender variations in coping mechanisms with men less likely to utilise formal or informal support systems. Poor coping strategies mean that the caregiver may perceive higher levels of burden and thus impact negatively on their health (Kramer, 2002; Ashley & Kleinpeter, 2002). Similarly, men who have to take up tasks that are seen to be women's responsibility through traditional gender-role socialisation may perceive caregiving as work overload unlike women who will feel competent performing the same tasks with minimal negative effects on their health (Fuller-Jonap & Haley, 1995; Kim et al., 2006).

There are two theoretical models advanced to explain the long-term impact of caregiving on the health of the caregivers. One is the 'wear and tear' model which posits that, the health of the caregiver continues to deteriorate progressively as they continue with caregiving tasks. This could continue even beyond the termination of the caregiving episode (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). On the other hand, the termination of care can lead to recovery and improvement in the caregiver's health as the caregiver is no longer exposed to the caregiving burden (Grasel, 2002). It is also evident that, a caregiver providing care to someone with a terminal condition may have time to prepare psychologically for the eventual outcome of death. Thus, making it easier to adjust to the situation after bereavement, and their health may not be adversely affected following the death of their care recipient (Schulz, Newsom, Fleissner, Decamp, & Nieboer, 1997). Conversely, the 'adaptation' model posits that with the passage of time a caregiver may be able to cope with the caregiver stress by embracing coping mechanisms or by learning to manage the caregiving tasks (Lawton, Moss, Hoffman, & Perkinson, 2000; Kramer, 2000).

A plausible reason to explain the variation in findings regarding the long-term effects of caregiving on the health of the caregiver may arise from the deviation in methodologies used by the various studies (Baumgarten, 1989). These differences include the selection process in recruiting study participants, diversity in the sub-groups of caregiver-care recipient dyads, and differences in the duration of follow-up. Furthermore, Seltzer and Li (2000) identified differences in outcome depending on the nature of the relationship between the caregiver and their care-recipient. Wives and daughters providing care to their spouse and parent respectively reported different health outcomes. The latter presenting with fewer negative consequences and were more likely to place their care recipient in institutional care, unlike wives caring for husbands. Findings from another study indicated that the time devoted to caregiving activities to be a key determinant of the effect of caregiving on health (Lawton *et al.*, 2000).

This paper adds to the literature in this field by examining transitions in caregiving status among a sample of older people who are providing care to people with AIDS within the context of a low resource setting, namely the slums of Nairobi. Using a unique longitudinal dataset, changes in health status over time across different caregiving pathways are assessed.

Methods

The study design and setting

Data are drawn from a population-based study conducted in the slums of Nairobi, Kenya. These slums occasioned by a rapid urbanization rate and inability of the city to cope (UNHABITAT, 2005), are characterised by unfavourable living conditions, poor health outcomes as well as high HIV prevalence rates (Zulu, Dodoo, & Ezeh, 2002). Nonetheless, urban areas in Kenya still enjoy advantages relative to rural areas in terms of livelihood opportunities, access to social services including health facilities and related HIV and AIDS programs.

The study participants were recruited from a database of residents of two slums (Korogocho and Viwandani) (Zulu *et al.*, 2011). Two waves of data are analysed, collected in 2006 and 2009. The baseline survey was conducted between October 2006 and January 2007 using interviewer-administered questionnaires after obtaining informed consent from the research participants. A total of 2,061 older people participated out of 2,696 eligible respondents, with the response rate at baseline of 76%. The follow-up interview was conducted between April and July 2009. Between the two waves, participants were lost to follow-up as a result of death (110 or 5%) and migration outside the study community (312 or 15%). Only 7% of the participants who were present during the follow-up study were unavailable for interview. The ethics clearance was issued by the Kenya Medical Research Institute (KEMRI/RES/7/3/1) which is mandated by the government of Kenya through the Ministry of Health to coordinate human research activities.

Identification of caregivers. A caregiver was identified as someone who was providing financial, instrumental, psychosocial, or nursing care to a person with a chronic illness (defined as any illness that had persisted for 3 months or longer), or someone who had provided care to a person with a chronic illness during the three years preceding the survey. In order to isolate care recipients who had an AIDS-related illness, an indirect approach was used because of lack of information on the HIV sero-status of the population. This approach is an adaptation of the WHO's AIDS case definition, which categorises a person as having developed AIDS, if he or she presents with at least two of the major signs of an AIDS case in combination with at least one of the minor signs. The presence of these major conditions or illness usually indicates advanced progression from asymptomatic HIV stage to full-blown AIDS. Overall, the WHO definition has very high specificity but low sensitivity (Grant & De Cock, 2001). This study categorised care recipients who were reported to be experiencing at least one of the major signs associated with an AIDS case as having an AIDS-related illness.

At baseline, about 11% (216) of older people reported that they were currently providing or had provided care to someone with a chronic illness within the past three years. Out of the 216 caregivers, 88 were classified as caring for someone with an AIDS-related illness (AIDS caregivers), whereas 128 were providing care to people with other illnesses (i.e. Other caregivers). Non-caregivers (1,845) represent older people who had not provided care to anyone with a chronic illness over the three-year period preceding baseline. There was no evidence of gender-bias as to whether men or women were more likely to be identified as caregivers. This may be the case because of the broad definition of caregiving adopted for this study where provision of care was defined as performing at least one form or a combination of financial, psychosocial, and personal or nursing care. A multidimensional definition of a caregiver that encompasses all aspects of care prevents a gender-biased identification of caregivers (Stone, 1991; Kramer, 2002).

During the follow-up interview, 65 HIV caregivers, 102 Other caregivers and 1,322 Non-caregivers were interviewed. There were no significant differences in loss to follow-up due to death between the three groups. However, AIDS caregivers and other caregivers were less likely to out-migrate compared with non-caregivers. On the other hand, the non-response rate among HIV caregivers (13%) was slightly higher compared with Other caregivers (6%) and Non-caregivers (9%). All the wave II participants were asked if they were currently caring for someone with a chronic illness, or if they had cared for someone in-between the two waves. In addition, individuals who were caregivers at wave I were asked if they were still caring for the same individual and, if not, the resulting outcome of that care episode.

Measures and analyses

Health status is measured using two self-assessed indicators: (i) the WHO Disability Assessment Score (WHODAS-12); and (ii) the presence of a severe illness or morbidity in the 3-month period prior to the interview. The WHODAS-12 is a generic multidimensional measure that assesses day-to-day functionality or disability at the physical, personal and social levels (WHO, 2009). It is based on a combination of six domains that comprise physical and psychosocial dimensions of wellbeing namely: mobility (walking, prolonged standing and being able to stand up quickly from sitting down); communication (ability to concentrate or learn a new task); self-care (capacity to perform activities of daily living); interpersonal interactions (measures difficulties with interacting with other people and dealing with conflicts or tensions); life activities (duties relating to domestic activities and household chores); and participation in society (joining or taking part in community activities). Mobility, communication, and self-care relate to physiological functioning whereas interpersonal interactions and life activities refers to personal level of functioning. Only one domain, participation in society, measures functioning at societal level. These domains or dimensions may vary on how responsive they are to stressors like caregiving. The participants were asked to assess 12 functionality items on a five-point Likert scale, and the questions were phrased in the manner *"In the last 30 days, how much difficulty/problems did you have with…"*. An overall disability score is generated by recoding the 12 items with a weight of either 2 or 4 as the maximum possible score. This is then summed and converted to a percentage to allow for comparison. The resulting scores, therefore, range from zero to 100 with higher scores indicating more functional impairment or higher disability.

The other health measure used is the presence of a severe health problem at the time of the study. The participants were asked the following question *"what do you consider being the most severe health problem you have currently?"* If the respondents mentioned more than one health problem, they were asked to state one they considered being the most severe. A binary variable is created indicating presence of any health problem coded 1, and reporting having no health problem at all coded 0.

The study participants were asked about the two health indicators at baseline and again at follow-up. At each interview, the time reference for the measures was the same, that is, the last 30 days for WHODAS-12, and at the time of interview for severe health problem. Therefore, repeated measures analyses were used to examine changes in disability based on the WHO Disability Assessment Score (WHODAS) measure and changes in reporting having a severe health problem. Time in the analyses refers to the data collection waves and in this case two time points. A random effect linear regression model using maximum likelihood estimation was fitted to investigate changes in WHODAS scores. A pooled logistic regression model was fitted to examine whether the reported change in presence of a severe health problem is associated with caregiving trajectories. Due to the small sample size, the numbers of parameters or covariates added to the models were kept at a minimal in order to capture the subtle differences between the caregiving transitions and changes in health. The baseline socio-demographic characteristics added in the models as potential confounders of health were age, marital status, and education. Interaction terms between time and caregiving status were also added in the models. Statistical significance was set at the 0.05 level. Separate analyses were conducted for men and women because gender is inherent in caregiving roles and tasks, and the fact that women consistently report higher levels of distress compared to men (Ashley & Kleinpeter, 2002; Anderson, 2003). Descriptive statistics of the sample and the transition in caregiving status between the first and second wave are first discussed. Results are presented according to the caregiving trajectories between the two waves.

Results

Socio-demographic characteristics of study participants

Table 1 presents the percentage distribution of the socio-demographic characteristics and other descriptive statistics of the study sample at baseline. The mean age of the participants was 58 years, and women were significantly older (60 years) compared with men (57 years). The sample is disproportionately male with 5 out of 8 individuals being men. This reflects the fact that migrants to the city are predominantly male, and that this bias is more marked among the older people who may have migrated to the city when the bias towards single male migrants was strong (Gould & Oucho, 1993). There were differences between AIDS caregivers, Other caregivers and Non-caregivers among women in particular, with regards to age and level of education (Table 1). Women who were AIDS caregivers and the Other caregivers were very similar in age (56.2 and 57.3 years respectively), whereas non-caregivers were significantly older (61.4 years). The three ‘care status’ groups were also significantly different in terms of the highest level of education attained. For instance, a higher proportion of AIDS caregivers (17%) had secondary education or higher, unlike only 6% of Other caregivers and 5% of Non-caregivers. The men, however, were not significantly different in age. However, only 11% of the AIDS caregivers had secondary education or higher compared with Other caregivers (23%) and non-caregivers (20%), unlike the women where a higher proportion of AIDS caregivers had secondary education or higher (Table 1).

Changes in caregiving status

Table 2 presents the trajectories in the caregiving status between the two waves of the study (2006-2009) comparing AIDS caregivers, other caregivers, and non-caregivers as identified at baseline. The majority of the caregivers did not change their role as caregivers during this period. About 69% (n=45) and 78% (n=80) of AIDS caregivers and other caregivers respectively were still providing care at the end of the study. Although, the majority of caregivers continued to provide care across the three years, a number of them took on new care recipients over this period. For instance, over two thirds (31 out of 45) of the AIDS caregivers whose status as caregivers did not change, were caring for a different care recipient from the one at baseline. Remarkably, six AIDS caregivers and four Other caregivers continued to provide care to the previous care recipient whilst taking on a new care recipient (not shown on table). About 31% (n=20) of AIDS caregivers and 22% (n=22) of Other caregivers reported having stopped providing care, whereas 13% of non-caregivers (n=166) had taken on a caring role (Table 2).

The transitions in caregiving status are categorised into six groups: (a) non-caregivers who did not change their status (‘never’ cared), (b) non-caregivers at baseline who took up the caregiving role (Never cared→caregivers), (c) continuing AIDS caregivers, (d) AIDS caregivers who discontinued caring (AIDS caregivers→Discontinued), (e) continuing Other caregivers, and (f) Other caregivers who discontinued caring (Other caregivers→Discontinued). A significantly higher proportion of AIDS caregivers ceased providing care because the care recipient died (14 out of 20), compared with other caregivers who were more likely to stop because the care recipients recovered from illness or changed residence, or for other reason such as someone else taking charge of the caring role (χ^2 12.4 [df,3] p = 0.006). Men and women did not differ in their likelihood of transiting from one caregiving status to another (χ^2 5.26 [df,5] p = 0.389). The pattern by age was however different. Individuals who never took on a caregiving role throughout the 3-year study period were significantly older compared with those who transitioned from non-caregivers to become caregivers (61 years vs 58 years; and 58 years vs 57 years for women and men respectively).

In the next section, these six groups are contrasted on the self-reported WHO Disability Assessment Score (WHODAS-12) and the presence of a severe illness or morbidity during the two time periods.

Changes in WHODAS-12 scores

Table 3 presents the descriptive statistics showing the absolute changes in the six WHODAS dimensions for men and women compared across care-giving status. On the whole, the study participants recorded an increase in disability over the three year period which is not surprising given the well documented correlation between health and age. A positive value in the absolute change indicates an increase in disability whereas a negative value suggests an improvement in health status between the two waves of the study. The changes in the disability scores observed for women were different to that observed for men. At the bivariate analysis, women who have never provided care (1.7), those who initiated caregiving (2.2) and AIDS caregivers who discontinued providing care (1.1) recorded an increase in disability overall. Those who have never provided care reported worse scores for all the domains except communication. Similarly, AIDS caregivers who discontinued providing care were worse of or remained the same across all the functionality domains except for interpersonal interaction.

Older people who initiated caregiving reported the largest absolute change in mobility scores (10.5) although they recorded improvements in other domains such as communication (-1.1), self-care (-4.4) and participation in society (-7.9). On the other hand, women who continued to provide care to someone with AIDS (-0.8), caregivers to recipients with other illnesses who continued to provide care (-0.1) and those who discontinued providing care (-3.2) reported a slight improvement in overall functionality with most of the improvement reported in the mobility domain. Among the men, only AIDS caregivers (continuing and discontinued) reported an improvement in functionality especially in the mobility domain with all the other caregiving groups reporting worsening conditions. Men who were AIDS caregivers at the start of observation but had stopped providing care, recorded the largest absolute improvement in overall functionality (-9.2) compared to other caregiving trajectories.

Table 4 and 5 presents the results of the repeated measures regression analyses of the disability dimensions and the overall disability score controlling for age, level of education, and marital status at baseline for men and women respectively. The interaction of time with caregiving status and disability was tested and found not to be significant. With other confounding factors accounted in the model, women who had provided care were not significantly different from those who have never provided care except for caregivers to persons with other illnesses who discontinued providing care. These women were significantly more likely to report an increase in disability scores compared with those who have never provided care. The significant differences were observed in three functionality domains namely: mobility; self-care; and interpersonal interaction. On the other hand, men who were still providing care to a person with AIDS recorded higher disability scores across several domains as well as the overall disability score compared with those who have never provided care. The domains are mobility, communication, and life activities. Caregivers to recipients with other illness who were still providing care at the end of the observation period and AIDS caregivers who discontinued providing care also reported significantly higher disability compared with older people who never provided care albeit in only one domain namely, mobility and life activities respectively.

Changes in severe health problem

The other health measure discussed in this paper is reported severe illness or morbidity at the time of interview. Table 3 also presents the percentage change in the proportion of men and women who reported having a severe health problem compared across the caregiving status. Overall, between the two waves, there was an increase in the proportion reporting to have a severe health problem. The largest increase was among those reporting to have an acute illness.

Among the women, the only groups with a decline in the proportion reporting a severe health problem were AIDS caregivers still providing care (-6%) and caregivers to recipients with other illness who had discontinued providing care by the end of the study (-17%). The largest percentage increase in the proportion reporting severe illness was among those who initiated caregiving (46%) whereas there was almost no change in the proportion reporting a severe health problem among those who never provided care during the observation period (<1%). The change in the proportion reporting severe illness or morbidity among baseline caregivers was, however, mixed. There was an increase (14%) in the proportion reporting a severe health problem among AIDS caregivers who stopped providing care, whereas the opposite was the case for caregivers to people with other illness who discontinued care (-17%). AIDS caregivers who were still providing care at the end of the observation period recorded a slight decrease in the proportion reporting a severe illness (-6%) while there was a substantial increase (43%) among other caregivers still providing care. Most of the increase in the proportion reporting to have a severe health problem is attributed to those reporting an acute illness as opposed to a chronic health condition.

Unlike the women, the change among the men in the proportion reporting a severe health problem between the two waves was consistent. There was a decline in the proportion reporting a severe health problem among men identified as caregivers at baseline. The greatest decline was observed among AIDS caregivers who had stopped providing care (-60%) with a slightly greater decline among those reporting a chronic condition (-62%) compared with those reporting an acute illness (-50%). The AIDS caregivers and other caregivers who were still providing care at the end of the observation period also recorded a decline in the proportion reporting a severe health problem albeit marginally at -26% and -20% respectively. The greatest increase in the proportion reporting a severe health problem is observed among men who took on a caregving role with a 100% increase with an overwhelming increase attributed to those reporting an acute illness. Similarly, men who were not caregivers during the entire period of the study also recorded an increase in the proportion reporting a severe health problem although the percentage change was comparatively minimal (33%).

Table 6 presents the odds ratio for the probability of reporting a severe health problem controlling for age, level of education and marital status. The models were run separately for men and women. Two sets of models are fitted, with and without the interaction terms. The interaction of time with caregiving status is significant (Model II). Among the women, those who initiated a caregiving role were less likely to report a severe health problem (OR 0.26; CI .076-0.87) compared to those who have never provided care however, over time they were up to 3 times more likely to report having a problem (OR 3.29; CI 1.69-6.40). Similar results are observed among the men where over time, those taking on a caregiving role were almost twice more likely to report having a health problem compared with those never provided care (OR 1.98; CI 1.41-2.79). The differences in the likelihood of reporting a severe health problem between women identified as caregivers at baseline and those not providing care were not statistically significant except for caregivers to people with other illnesses who were still providing care at the end of the study. This caregivers although less likely to report having a health problem initially were twice more likely after baseline to report a severe health problem (OR 2.27; CI 1.02-5.02) compared to those who have never provided care. On the other hand, men who continued to provide care during the duration of the study were more likely to report having a severe health problem compared with those who never provided care. The likelihood decreased significantly over time for caregivers to people with other illnesses (OR 0.45; CI 0.29-0.70) but not for AIDS caregivers (OR 0.47; CI 0.24-0.92).

Discussion and conclusion

This paper sought to understand the transitions in caregiving status over a 3-year period among a population of older people living in a slum area in Nairobi, Kenya. The caregivers included those providing care to people with AIDS. The study has highlighted the prolonged nature of caregiving as a majority of caregivers identified at the beginning of the study were still providing care three years on. Earlier research from sub-Saharan Africa pointed to relatively short durations ranging from just a few months (Chimwaza & Watkins, 2004) to about two years (Ssengonzi, 2009). The result in the current study may be a pointer to the improvement in the care and management of people with HIV and AIDS, consequently resulting in prolonged duration of care. Another explanation may relate to enhancement in access to antiretroviral therapy (ART), which has improved overall from as low as 7% of people in need of ART accessing treatment in 2003 to almost half (42%) in 2008 (UNAIDS, 2010). This has led to improvement in the survival rates of people with HIV and AIDS (Boulle & Ford, 2008).

Another significant finding relating to caregiving trajectories was the tendency for caregivers to undertake more than one caregiving episode over the period of observation. One explanation may relate to the clustering of HIV infection in households or families. In the study context and generally across sub-Saharan Africa, the main route of transmission is through heterosexual intercourse. The chances of the older caregiver providing care to more than one person, sometimes concurrently, are hence increased (Dayton & Ainsworth, 2004; Ssengonzi, 2009). Therefore, the care recipients may be related through marriage, having contracting the virus through sexual intercourse, or they may be a parent-child relationship for cases where infection occurs through vertical transmission from mother to child during birth or breastfeeding. An additional explanation to multiple care experiences may arise from the lack of formal care systems for people with AIDS and for this reason having to rely on the family and kin for almost all forms of support. The probability of being a caregiver may, therefore, not be random with certain individuals more likely to be caregivers than others based on their ability as well as willingness to take on caregiving (Ice *et al.*, 2010).

The other objective of this paper was to examine changes in health status over time compared across the different caregiving pathways. Two self-assessed indicators are used, one that measures functionality based on multiple dimensions and another on reporting the presence of a severe illness or morbidity.

Women identified as AIDS caregivers at baseline did not differ significantly from non-caregivers in reporting disability or having a severe illness when socio-demographic characteristics are taken into account, and this did not change over time. The situation is, however, different for men where caregivers presented with significantly higher disability scores compared to those who have never provided care. The gender differences observed on the extent of the effect of caregiving on health is particularly interesting. Men who are caregivers report poorer health compared with non-caregivers whereas no differences is observed for women. Drawing on related empirical research, this finding can be explained by the differences between the genders on how they respond to stressors as well as variation in coping strategies. Although a number of studies emphasize that men and women are exposed to similar levels of stress as a result of providing care (Miller & Cafasso, 1992), what varies between the genders may relate to the differential approach to coping (Anderson, 2003; Kim et al., 2006). Nonetheless, there is an improvement over time among the male caregivers. It can be argued that this is suggestive of an adaptation process observed over time among the male caregivers in this study. This process may result from a number of pathways one of which relates to the caregivers becoming more accustomed to tasks and responsibilities of caregiving thereby perceiving less of a burden compared with the initial stages of providing care. The other pathway is through cessation of caregiving hence the source of burden and stress is lifted. In turn, the health of the caregiver gradually begins to improve. It has been hypothesized that compared with women, men tend to adopt coping strategies that are more efficient and effective and this could thus explain the improvement in health among men over time (Lutzky & Knight, 1994).

Another key finding in the study is that older people who became caregivers after the baseline survey (men and women) were increasingly more likely to report poor health over time even though they initially presented with better health, compared with those who have never provided care. For instance, men and women who became new caregivers were 54% and 74% less likely respectively to report a severe health problem but over time they had increased odds of reporting a severe health problem compared with their older counterparts who have never provided care. This could imply that the new caregivers are faced with unfamiliar responsibility thus elevating the level of burden and stress associated with caregiving. The most commonly reported health problem was having an acute illness. It is widely documented that stressful life events and perceived burden are known to be associated with a supressed immune function and, therefore, susceptibility to diseases particularly those that are infectious such as respiratory illnesses (Cohen & Williamson, 1991; Shaw et al., 1997).

It is necessary to highlight the limitations in this study. One key challenge was the small sample size resulting in the lumping of caregivers in large aggregate groups thus not taking into account heterogeneity among caregivers and allowing for the effects for certain types of caregivers. In particular, bearing in mind the circumstances surrounding the care episode such as the actual time when the care event started or ended; the specific care tasks performed by the various caregivers; the changes associated with the care recipient; and the social environment specific to the caregivers' situation would have provided a nuanced account of caregiving transitions and changes in health. These criticisms notwithstanding, the findings in the paper provide some pointers for policy and programmes seeking to prevent or minimise the negative impact on the health outcomes among caregivers.

Disability is one of the key indicators used to assess the health and wellbeing of older people. The findings from this study indicate that some and not all the functionality domains were significantly associated with being a caregiver. In particular, the domains most affected (mobility, self-care, communication and life activities) are the core domains that are specific to the physiological and psychological functioning and thus central to activities of daily living (ADL) and instrumental activities of daily living (IADL). Disability in these domains is closely linked with underlying medical conditions. There is need to prevent further progression of disability and or reverse the trend by addressing the underlying cause risk factors including reducing the amount of caregiving burden that is borne by the caregivers.

In sub-Saharan Africa, informal caregivers will continue to provide vital care and support to people infected with HIV and AIDS particularly due to the inability of the healthcare systems or social services to absorb the bulk of the care needs for people with AIDS. Furthermore, services and programs to assist caregivers - majority of whom are older people - with caregiving responsibilities are virtually lacking. This paper highlights that caregiving places these older people at risk of poor health particularly at the start of caregiving episode although their health improves with time. Therefore, interventions to reduce the negative impact of caregiving should be targeted particularly at the initiation of caregiving. This research underscores the need for HIV and AIDS policies and programmes to pay attention to caregivers who provide invaluable contribution in the care and management of the epidemic as the focus has largely been on people living with HIV and AIDS, and to orphans. For a start, caregiver interventions and support services for people affected by HIV and AIDS need to be put in place and awareness raised at the national and community levels on the services and programs that people can tap into. These programmes also need to take into consideration the gendered nature of caregiving effect of health as the findings in this paper draw attention to male caregivers with worse health outcomes.

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Table 1: Socio-demographic characteristics of study participants by sex and caregiving status at baseline[1]

	All sample			Women			Men		
Socio-demographic variables	**Women**	**Men**	**Total**	**AIDS-Caregivers**	**Other caregivers**	**Non-Caregivers**	**AIDS-Caregivers**	**Other caregivers**	**Non-Caregivers**
***Mean Age*‡**	*60.2*	*57.4*	*58.5*	*56.2*	*57.3*	*61.4*	*57.2*	*57.3*	*58*
Age Group									
50-54	39.2	45.6	43.1	43.3	59.4	37.8	45.7	45.7	45.5
55-59	18.5	27.8	24.2	30.0	15.6	18.4	34.3	35.7	26.7
60-64	15.3	13.6	14.2	20.0	9.4	15.1	14.3	12.9	13.8
65-69	26.9	13.1	18.4	6.7	15.6	28.7	5.7	5.7	14.0
Marital Status†									
Currently married	31.7	90.6	68.2	43.3	34.4	31.2	97.1	95.7	90.5
Divorced/separated	18.0	4.2	9.5	16.7	21.9	18.0	0.0	1.4	4.3
Widowed	41.1	4.2	18.3	33.3	31.3	41.5	2.9	2.9	4.3
Never married	9.2	1.0	4.1	6.7	12.5	9.3	0.0	0.0	0.9
Highest level of									

education[↕]									
No education	51.3	20.9	32.5	43.3	15.6	54.1	0.0	4.3	22.8
Primary	42.9	59.8	53.3	40.0	78.1	40.9	88.6	72.9	57.6
Secondary	5.8	19.3	14.2	16.7	6.3	5.0	11.4	22.9	19.6
Total	100	100	100	100	100	100	100	100	100
n	578	911	1,489	30	32	516	35	70	806

[1] $\chi 2$ test conducted to determine between-gender and caregiving status differences

[‡] Significant differences between men and women, and between women caregivers and women non-caregivers

[†] Significant differences between men and women but not across caregiving status

[↕] Significant differences between men and women, and across caregiving status

Table 2: Changes in status (2006 – 2009) compared across caregiving status at baseline

	n	Same Status	New care episode	Discontinued care
AIDS Caregivers	65	14	31	20
		(21.5)	(47.7)	(30.8)
Other Caregivers	102	32	48	22
		(31.4)	(47.1)	(21.6)
Non-caregivers	1,322	1,156	166	0
		(87.4)	(12.6)	0.0

Table 3: Descriptive analysis for WHODAS-12 and reported severe health problem for men and women by caregiving status

	Absolute changes in WHODAS-12 dimensions and overall score							Percent change in reported severe health problem			
	Mobility	Communication	Self-care	Interpersonal interaction	Life activities	Participation	Overall functionality	no severe problem	Acute illness	Chronic illness	Total reporting illness
Men											
Never cared	2.5	-2.9	-0.4	2.9	1.8	-0.1	0.7	-24.8	103.9	7.9	32.3
Never cared >caregivers	6.8	0.5	-1.4	9.2	3.9	6.4	4.2	-67.7	206.7	44.8	100.0
other caregivers >Discontinued	2.5	2.5	2.2	8.3	6.7	6.7	4.4	16.7	0.0	-25.0	-11.1
Continuing other caregivers	-2.9	-5.6	1.8	5.8	8.0	8.0	1.0	84.7	-22.7	-28.6	-25.6
AIDS caregivers >Discontinued	-25.0	-8.8	-5.0	0.0	-10.0	5.0	-9.2	[a]	-50.0	-62.5	-60.0
Continuing AIDS caregivers	-6.5	-15.5	-6.0	5.5	-2.0	12.0	-4.2	80.0	125.0	-56.3	-20.0
All sample	2.2	-3.0	-0.5	3.9	2.3	1.6	0.9	-24.8	88.0	3.2	28.0
Women											
Never cared	0.6	-0.1	1.6	4.5	2.2	1.7	1.7	-1.3	95.1	-20.1	0.5
Never cared >caregivers	10.5	-1.1	-4.4	5.0	1.3	-7.9	2.2	-85.0	87.5	34.5	46.0
other caregivers >Discontinued	-16.1	-5.4	4.8	7.1	-7.1	0.0	-3.2	99.9	[b]	-16.7	-16.7
Continuing other caregivers	-6.3	-1.6	4.2	2.6	2.1	2.1	-0.1	-60.0	250.2	8.3	42.9
AIDS caregivers >Discontinued	0.0	6.3	1.7	-3.8	2.5	0.0	1.1	-33.3	100.0	-20.0	14.3

Continuing AIDS caregivers	-13.8	1.9	-2.5	6.3	0.0	15.0	-0.8	33.3	200.0	-50.0	-5.9
All sample	0.6	-0.2	1.0	4.4	1.9	1.1	1.5	-13.7	103.2	-15.3	6.0

[a] There were no AIDS caregivers who discontinued providing care who reported not having a severe health problem at baseline. In wave II, 60% reporting not having any severe health problem.

[b] None of the caregivers to persons with other illness who discontinued providing care reported an acute health problem either at baseline or during the follow-up survey.

Table 4: Repeated measures regression estimates of WHO Disability score by caregiving status adjusting for age, education level and marital status (MEN)

	Mobility	**Communication**	**Self-care**	**Interpersonal skills**	**Life activities**	**Participation**	**Overall functionality**
Caregiving trajectory	Coefficient (SE)	Coefficient (SE)	Coefficient (SE)	Coefficient (SE)	Coefficient (SE)	Coefficient (SE)	Coefficient (SE)
Never cared (Ref)							
Never cared >caregivers	1.028 (1.721)	1.544 (1.300)	-1.572 (1.082)	1.359 (1.286)	1.781 (1.712)	1.066 (1.724)	0.870 (1.090)
other caregivers >Discontinued	-5.031 (4.425)	-2.781 (3.345)	-3.263 (2.782)	-6.189 (3.306)	-6.489 (4.406)	-8.190 (4.438)	-4.826 (2.803)
Continuing other caregivers	5.619 (2.333)*	0.315 (1.762)	-1.062 (1.466)	-0.999 (1.742)	-1.762 (2.320)	-1.215 (2.336)	0.657 (1.477)
AIDS caregivers >Discontinued	7.097 (5.328)	5.252 (4.024)	-1.464 (3.349)	-0.321 (3.979)	17.181 (5.299)**	-5.791 (5.335)	4.017 (3.374)
Continuing AIDS caregivers	9.126 (3.416)**	7.887 (2.580)**	2.400 (2.148)	3.841 (2.551)	10.508 (3.398)**	0.358 (3.421)	6.224 (2.163)**
Age	0.703 (0.079)***	0.313 (0.059)***	0.237 (0.049)***	0.290 (0.059)***	0.589 (0.078)***	0.325 (0.079)***	0.413 (0.050)***
Highest level of education							
No education (Ref)							
Primary	-2.458 (1.483)	-1.597 (1.121)	-1.727 (0.932)	-1.205 (1.108)	-2.201 (1.476)	-3.449 (1.486)*	-1.898 (0.939)*
Secondary	-3.861 (1.861)*	-1.243 (1.406)	-1.916 (1.170)	-1.108 (1.390)	-2.913 (1.852)	-1.944 (1.864)	-2.137 (1.179)
Marital Status							
currently married (Ref)							

Divorced/separated	0.686 (3.663)	2.709 (2.827)	4.920 (2.309)*	3.012 (2.780)	5.374 (3.775)	9.834 (3.847)*	3.454 (2.336)
Widowed	7.986 (3.676)*	4.211 (2.836)	2.282 (2.313)	2.729 (2.785)	8.839 (3.782)*	12.146 (3.853)**	5.263 (2.345)*
Never married	5.612 (7.486)	0.690 (5.775)	6.564 (4.720)	9.184 (5.671)	11.372 (7.701)	14.795 (7.851)	6.623 (4.770)
Wave	-1.600 (3.738)	-1.695 (2.884)	-3.434 (2.357)	-2.470 (2.832)	-4.253 (3.847)	-6.110 (3.922)	-2.667 (2.382)
Constant	-15.307 (6.362)	-0.161 (4.847)	-1.711 (4.004)	3.079 (4.779)	-7.692 (6.417)	1.796 (6.495)	-3.778 (4.039)

Statistical significance levels *** <0.001; **<0.01 *<0.05

Table 5: Repeated measures regression estimates of WHO Disability score by caregiving status adjusting for age, education level and marital status (WOMEN)

	Mobility	**Communication**	**Self care**	**Interpersonal skills**	**Life activities**	**Participation**	**Overall functionality**
Caregiving trajectory	Coefficient (SE)	Coefficient (SE)	Coefficient (SE)	Coefficient (SE)	Coefficient (SE)	Coefficient (SE)	Coefficient (SE)
Never cared (Ref)							
Never cared >caregivers	3.116 (2.894)	3.517 (2.156)	-0.522 (1.840)	2.112 (2.026)	2.519 (2.893)	-1.980 (2.863)	2.024 (1.849)
other caregivers >Discontinued	23.909 (7.549)**	9.731 (5.644)	9.931 (4.821)	12.293 (5.298)*	11.546 (7.547)	5.844 (7.486)	13.743 (4.819)**
Continuing other caregivers	-1.870 (4.471)	-0.648 (3.328)	-4.414 (2.841)	-2.619 (3.129)	0.891 (4.468)	-2.467 (4.421)	-1.912 (2.857)
AIDS caregivers >Discontinued	7.940 (6.615)	0.858 (4.924)	-5.419 (4.204)	-1.851 (4.629)	-5.379 (6.610)	-12.521 (6.541)	-0.629 (4.226)
Continuing AIDS caregivers	7.187 (4.777)	4.628 (3.557)	-2.724 (3.036)	4.336 (3.344)	3.187 (4.774)	4.417 (4.725)	3.752 (3.052)
Age	0.826 (0.101)***	0.604 (0.076)***	0.381 (0.065)	0.462 (0.071)***	0.822 (0.101)***	0.583 (0.100)***	0.608 (0.065)***
Highest level of education							
No education (Ref)							
Primary	-4.800 (1.891)*	-1.701 (1.409)	-1.988 (1.202)	-2.331 (1.324)	-4.025 (1.890)*	-5.673 (1.871)**	-3.046 (1.208)*
Secondary	-7.509 (3.957)	-1.320 (2.947)	-1.915 (2.515)	-1.574 (2.770)	-4.142 (3.954)	-1.371 (3.914)	-3.148 (2.528)
Marital Status							
currently married (Ref)							

Divorced/separated	3.367 (3.164)	0.015 (2.551)	-2.432 (2.198)	0.385 (2.343)	-2.528 (3.191)	-0.730 (3.306)	0.233 (1.973)
Widowed	3.915 (2.592)	4.270 (2.096)*	0.556 (1.809)	3.392 (1.924)	0.990 (2.614)	1.234 (2.714)	2.851 (1.615)
Never married	8.409 (4.023)*	4.072 (3.242)	1.703 (2.804)	3.588 (2.981)	3.061 (4.057)	5.627 (4.205)	4.782 (2.510)
	-2.457 (1.811)	-1.172 (1.470)	-0.423 (1.272)	1.182 (1.348)	-0.497 (1.828)	-1.808 (1.903)	-0.877 (1.128)
Constant	-10.281 (6.798)	-15.099 (5.121)	-10.683 (4.380)	-6.070 (4.796)	-15.559 (6.801)	-12.127 (6.776)	-11.186 (4.330)

Statistical significance levels *** <0.001; **<0.01 *<0.05

Table 6: Logistic regression modelling the probability of reporting a severe health problem by caregiving status adjusting for age, education level and marital status

	Women		**Men**	
	Model I **Odds Ratio (SE)**	**Model II** **Odds Ratio (SE)**	**Model I** **Odds Ratio (SE)**	**Model II** **Odds Ratio (SE)**
Age	1.038 (0.012)**	1.040 (0.012)**	1.024 (0.008)**	1.025 (0.008)**
Highest level of education				
No education (Ref)				
Primary	0.779 (0.157)	0.775 (0.163)	0.860 (0.115)	0.854 (0.121)
Secondary	0.693 (0.286)	0.688 (0.296)	0.751 (0.126)	0.741 (0.132)
Marital Status				
Currently married (Ref)				
Divorced/separated	1.976 (0.670)*	2.004 (0.697)*	1.686 (0.584)	1.838 (0.660)
Widowed	1.976 (0.554)	1.954 (0.563)*	1.147 (0.393)	1.166 (0.415)
Never married	1.511 (0.651)	1.542 (0.685)	1.622 (1.136)	1.733 (1.253)
Caregiving trajectory				
Never cared (Ref)				
Never cared >caregivers	2.037 (0.664)*	0.257 (0.160)*	1.632 (0.258)**	0.464 (0.166)*
Other caregivers >Discontinued	2.403 (2.087)	7.569 (14.748)	1.348 (0.537)	3.844 (3.386)
Continuing other caregivers	1.281 (0.596)	0.275 (0.240)	2.247 (0.498)***	11.671 (6.252)***
AIDS caregivers >Discontinued	1.578 (1.139)	0.851 (1.170)	2.370 (1.225)	-
Continuing AIDS caregivers	3.385 (1.974)*	6.959 (8.423)	2.994 (1.012)**	14.084 (11.539)**
Caregiving trajectory*time				
Never cared*time (Ref)				
Never cared >caregivers*time		3.293 (1.116)***		1.985 (0.344)***
Other caregivers >Discontinued*time		0.593 (0.452)		0.590 (0.231)
Continuing other caregivers*time		2.268 (0.919)*		0.450 (0.101)***

AIDS caregivers >Discontinued*time		1.379 (0.831)		0.000 (0.085)
Continuing AIDS caregivers*time		0.714 (0.350)		0.474 (0.161)
wave	1.145 (0.225)	1.013 (0.209)	1.055 (0.369)	1.048 (0.378)
-2 log likelihood ratio	-646.90	-636.57	-1233.40	-1195.38
Chi-square statistic (DF)	34.0 (12)**	44.8 (17)**	72.9 (12)***	99.7 (17)***

Statistical significance levels *** <0.001; **<0.01 *<0.05