

Title: Health of Older Caregivers for People with AIDS: A Prospective Study of Older People Living in Nairobi Slums, Kenya

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Introduction

HIV/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 *et al.*, 2001; Dayton & Ainsworth, 2004). Within the family, older people play a key role in caring for people with AIDS. In Thailand for instance, close to three quarters of the people with AIDS were cared for by older people (Knodel *et al.*, 2001) and similar findings were reported in Uganda (Ntozi & Nakayiwa, 1999). Older people assume the role of caregivers as a filial obligation given that they are mostly parents to the people with AIDS. On the other hand, older people act and perform this responsibility as heads of households or families as a normative practice particularly for communities in Africa and Asia (Ntozi & Nakayiwa, 1999; WHO, 2002).

There are two theoretical models that have been 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 tasks of caregiving and sometimes even beyond the termination of the caregiving episode (Kiecolt-Glaser *et al.*, 1991; Aneshensel *et al.*, 1995; Hirst, 2005). Conversely, the termination of care either through death, institutionalization and other reasons can lead to recovery and improvement in the health of the caregiver. This arises as the caregiver is no longer exposed to the caregiving burden and is able to devote time and resources towards their own health (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 *et al.*, 1997). The other explanatory hypothesis, the adaptation model posits that a caregiver can be able to cope with the caregiving stress by embracing coping mechanisms or by learning to manage the caregiving tasks. For instance a study following up women who were taking care of their ailing parents found that their physical and psychological health remained stable over time even amidst heavy caregiving burden (Lawton *et al.*, 2000). Another study looking at the long term effects of caring for a spouse with dementia had similar findings where the health of husbands providing long-term care did not deteriorate although the condition of their spouse under their care continued to deteriorate (Kramer, 2000).

Methods

The study design and setting

Data are drawn from a population-based study with two waves of data collected in 2006 and 2009 aimed at understanding the wellbeing of older people living in the slums of Nairobi, Kenya. The study participants were recruited from a database of usual residents of two slums (Korogocho and Viwandani) updated every four months since 2002 (APHRC, 2010). All people 50 years and older who were resident in the two slums during the round of update preceding the baseline survey were eligible for

interview. The baseline survey was conducted between October 2006 and January 2007 using interviewer-administered questionnaires. A total of 2,061 older people were interviewed out of a possible 2,696 eligible respondents therefore the response rate at baseline was 76%. The follow-up interview was conducted between April and July 2009. Between the two waves, 110 (5%), and 312 (15%) participants were lost to follow-up as a result of death and migration outside the study community respectively. Only 7% of the participants who were present during the follow-up study were unavailable for interview.

Identification of caregivers

About 11% (216) of older people reported at baseline to be providing or to have provided care to someone with a chronic illness. 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 (Other caregivers). Non-caregivers (1,845) are therefore older people who had not provided care to anyone with a chronic illness over the three-year period preceding baseline. There was no inclination as to whether men or women were more likely to be identified as caregivers. This may be because a broad definition of caregiving was 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. Thus a multi-dimensional definition 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 HIV caregivers and other caregivers were less likely to out-migrate compared with non-caregivers. Conversely, 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 taking care of someone with a chronic illness or if they had cared for someone in-between the two waves. In addition, individuals who were carers 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 was measured using two indicators: (i) the WHO Disability Assessment Score (WHODAS-12); and (ii) presence of a severe illness or morbidity in the 3-months period prior to the interview. The WHODAS-12 is a multidimensional measure that assesses day-to-day functionality or disability at the physical, personal and social levels. WHODAS was designed as a generic disability measure and not tailored for a specific disease or age (WHO, 2009). It is based on six different domains: understanding and communication (cognition); getting around (mobility); self care (hygiene, dressing, eating alone); interpersonal interactions (getting along); life activities (domestic responsibilities and work); and participation in society (community activities). 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...*”. A score for each of the domains was generated by recoding the 12 items with a weight of either 2 or 4 as the maximum possible score which is then summed and converted to a percentage to allow comparison across domains. The resulting score therefore ranges from zero to 100 with higher scores indicating more functional impairment. The overall disability

score is an aggregate of the six domains thus combines both physical and psychosocial dimensions of disability. Caring for someone with a chronic condition can be a risk factor as it can impact on functioning or lead to an acceleration of decline in functionality (Vitaliano *et al.*, 2004). To assess the presence of disease or general poor health the participants were asked the following question “*what do you consider to be 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 to be the most severe.

Results

Changes in caregiving status

The majority of the caregivers did not change their caring status during the period of observation with 69% (n=45) and 78% (n=80) of AIDS caregivers and other caregivers were still providing care at the end of the study. Although majority of the carers continued to provide care during the panel, a number of them took on new care recipients. For instance, over two thirds (31 out of 45) of the AIDS caregivers whose status as carers did not change were caring for a different care recipient from the one at baseline. Notably, six AIDS caregivers and four other caregivers continued to provide care to the previous care recipient whilst taking on a new care recipient. About 31% (n=20) of AIDS caregivers and 22% (n=22) of other caregivers reported to have stopped providing care whereas 13% of non-caregivers (n=166) had taken on a caring role. 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 the illness or changed address (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 as individuals who remained as non-caregivers throughout the 3-year study period were significantly older compared with those who transitioned from non-caregivers to become carers (61 years vs 59 years; and 58 years vs 57 years for women and men respectively).

Changes in WHODAS-12 scores

On the whole, the study participants recorded an increase in disability across all the domains except in cognition and mobility domains for men and women respectively. Among the men, those who were AIDS caregivers at Wave I recorded an improvement in functionality overall compared with those who were non-caregivers. In particular, an improvement in functionality was noted in the mobility, cognition, and self-care domains. The men who were AIDS caregivers at the start of observation but had stopped providing care recorded the largest absolute improvement in functionality overall (-9.2) compared to other categories of caregiving trajectories with the greatest change reported in the mobility domain (-25.0). Similarly, these AIDS caregivers who stopped providing care reported an improvement in life activities domain (-10.0) whereas all the other study participants recorded a functioning decline in this domain. Men who provided care over the entire period of the study recorded deterioration in interpersonal interactions, life activities and participation in society domains although there were improvements in the rest of the domains. On the other hand, those who did not provide care at all during the duration of the study recorded worsening functionality status overall except for the self-care (-0.4) and cognition (-2.8) domain.

The absolute changes in the disability scores observed for women were different to that of men. Women who were caregivers during the entire duration of the study recorded improvement in functionality overall (-0.1 for other caregivers and -0.8 for AIDS caregivers) compared with the other categories of care transitions. The pattern emerging in the specific domains compared across caregiving status is however not consistent. For instance AIDS caregivers who stopped providing care recorded a decline in functionality across all the domains except for interpersonal interactions (-3.8) whereas other caregivers who stopped providing care recorded declines in functionality in all the domains except for mobility (-12.9) and life activities (-2.2) domain. Women who were not caregivers over the entire period of the study recorded declining functionality (1.3) except for cognition domain (-0.6), those who took on caregiving however showed improvement in cognition, self-care, and participation in society domains.

Repeated measures analysis of the 6 disability domains and the overall score was performed controlling for age, level of education, and marital status at baseline for men and women respectively. Men who were AIDS caregivers but had stopped providing care and those who were still providing care at the end of the study were significantly more likely to record higher disability scores for the mobility ($\beta=35.0$, $p=0.001$; $\beta=18.2$, $p=0.009$ respectively) and life activities ($\beta=29.7$, $p=0.009$; $\beta=14.7$, $p=0.044$ respectively) domain as well as overall functionality ($\beta=14.3$, $p=0.040$; $\beta=11.4$, $p=0.011$ respectively) compared with those who have never provided care when other factors are accounted for. Nonetheless, there was significant interaction with time among previous AIDS caregivers ($\beta=-13.9$, $p=0.003$) and continuing AIDS caregivers ($\beta=-6.4$, $p=0.007$) whose disability scores on mobility and cognition respectively improved over time. Men who took on a caregiving role after baseline recorded an increase in disability over time particularly for interpersonal interaction ($\beta=3.1$, $p=0.007$) although they reported better functionality across the domains compared with those who have never provided care.

Differences in disability scores for women who have ever provided care compared with those who have never provided care were not statistically significant across almost all the functionality domains after accounting for the effect of age, education and marital status. Only the differences in the mobility domain by caregiving status was statistically significant where other caregivers who had stopped providing care ($\beta=38.7$, $p=0.007$) and AIDS caregivers who were still caring ($\beta=22.2$, $p=0.011$) reported significantly higher disability scores compared to those who have never provided care. Over time, continuing AIDS caregivers recorded an improvement in mobility ($\beta=-7.5$, $p=0.040$) whereas women who took on a caregiving role recorded an increase in disability in the mobility domain ($\beta=4.7$, $p=0.012$) while recording an improvement in participation in society ($\beta=-4.9$, $p=0.046$) compared with those who have never provided care.

Changes in severe health problem

Overall, there was an increase in the proportion of the study participants reporting a severe health problem between the two Waves. However, among the men, there is a reduction in the proportion reporting a severe health problem among older people who were caregivers at baseline whereas the opposite is true for non-caregivers. Only 4 out of 10 of the AIDS caregivers who had stopped providing care at the end of the study period reported having a severe health problem unlike at baseline where all reporting

having a health problem. The women do present a different pattern from the men. The absolute percent change was not substantial across almost all the categories except for women who took on caregiving roles during the observation period where almost all (95%) reported having a severe health problem at Wave II compared to about two thirds at the beginning of the study. There was a general increase in the proportion reporting a severe health problem across all the caregiving categories with the exception of other caregivers who stopped providing care and AIDS caregivers who were still providing care although the percentage change was minimal.

The results of logistic regression modelling show that men (OR 0.46; CI 0.23-0.93) and women (OR 0.26; CI 0.08-0.87) who took on a caregiving role after baseline were significantly less likely to report a severe health problem compared with those who have never provided care at all. On the other hand, men who were still providing care were significantly more likely to report a severe health problem compared with the reference group (never cared). The interaction between caregiving and time was statistically significant. Both men and women who took on a caregiving role had about 2 and 3 times higher likelihood of reporting a severe health problem over time respectively compared with those who have never provided care. The likelihood however decreased for men who continued to provide care throughout the study period by around 55% while the opposite was true for women who were still providing care to recipients with other illnesses (OR 2.27; CI 1.02-5.02).

Conclusion

The study has highlighted the prolonged nature of caregiving as a majority of carers identified at the beginning of the study were still providing care three years on. Earlier research from sub-Saharan Africa that looked at the duration taken by AIDS carers in providing care to people with AIDS 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 is therefore a departure from previous finding and it appears that the improvement in the care and management of people with HIV and AIDS consequently resulting in prolonged duration of care may be a factor. Another explanation may relate to enhancement in access to antiretroviral therapy (ART) which has massively improved overall from as low as 7% of the people in need of ART accessing treatment in 2003 to almost half (42%) in 2008 across the countries in the region (UNAIDS, 2010). This has led to improvement in the survival rates of people with HIV and AIDS (Bussmann *et al.*, 2008; Boulle & Ford, 2008; Alemu & Sebastian, 2010) notwithstanding challenges such as drug resistance or monitoring and evaluation of studies (Bisson *et al.*, 2008).

Another important finding in this study relating to caregiving trajectories was the tendency for carers 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 particularly in this context where the main route of transmission is through heterosexual intercourse as is the case throughout sub-Saharan Africa. The chances of the older carer providing care to more than one person sometimes concurrently are therefore increased (Dayton & Ainsworth, 2004; Ssengonzi, 2009). In this regard, the care recipients cared for by the same older person 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 these reason having to rely on the family and kin for almost all forms of support. The probability of being a carer may therefore not be random with certain individuals more likely to be carers than others based on their ability as well as willingness to care (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, one that measures functionality based on multiple dimensions and another on reported presence of a severe illness or morbidity are used. The dimensions relating to physiological functioning (mobility and cognition) and instrumental functioning (life activities and interpersonal interaction) were most affected by caregiving status particularly among older men. In particular, caregivers especially men who were providing care to people with AIDS reported significantly higher disability in the aforementioned domains of functioning compared with older men who have never provided care. Among the women, caregivers including continuing AIDS caregivers and other caregivers who had stopped providing care had significantly higher disability scores only in the mobility domain compared with older women who had never provided care. The findings from this study support widely documented evidence of the effects of caregiving on physiological or physical health that occurs due to exertion of the caregiving tasks resulting in musculoskeletal strain, exacerbation of existing health condition, neglect of own health, and elevation of stress levels which increase susceptibility to infections (Pearlin *et al.*, 1981; Aneshensel *et al.*, 1995). The gender differences observed in this study on the extent of the effect of caregiving on health and on the specific domains of functioning that are affected is particularly interesting. Men who are carers reported poor functioning in a number of physiological and instrumental domains compared with non-caregivers whereas women caregivers reported poor functioning only in the mobility domain when compared with those who have never provided care. 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. Whereas a number of studies emphasize that men and women are exposed to similar levels of stress due to caregiving (Miller & Cafasso, 1992; Pinquart & Sorensen, 2006) what varies between the genders is the approach to coping with women utilising social networks and emotional support as coping strategies much more than men. This may therefore explain the fact that while both men and women caregivers in this study report poor physical health specifically in the mobility domain, only the male caregivers reported difficulty with life activities and interpersonal interaction compared to male non-caregivers. Unlike men, women will draw on support from social networks or formal channels thereby not severely restricting social interaction or the ability to maintain contact with networks outside the home (DeVries *et al.*, 1997; Ashley & Kleinpeter, 2002; Anderson, 2003; Kim *et al.*, 2006).

This paper draws attention to the fact that while caregivers presented with higher disability scores compared to those who have never provided care, nonetheless there is an improvement over time among AIDS caregivers who stop providing care as well as those who continue to provide care over the three years. These improvements are more marked among men (continuing and former AIDS caregivers) who over time were also less likely to report having a severe health problem compared with those who have never provided care. It can be argued that this is suggestive of an adaptation

process observed over time among the 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 and or through cessation of caregiving hence the source of burden and stressors is lifted. In turn, the health of the caregiver gradually begins to improve. Furthermore, another key finding to augment the adaptation hypothesis is that older people who became caregivers after the baseline survey were increasingly more likely to report poor health over time even though they 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.