The Impact of Caregiving on the Health and Well-being of Kenyan Luo Grandparents

Gillian Ice, Elizabeth Juma, Jaja Yogo

In the wake of the HIV/AIDS crisis, African grandparents are taking on more responsibility for their grandchildren’s care. In 2005, an estimated 24.5 million Africans were living with HIV/AIDS accounting for approximately 64% of global HIV/AIDS cases (UNAIDS, 2006). The high mortality rate of adults with HIV/AIDS has produced approximately 12 million orphans whose care has largely been left to grandparents and other relatives (UNAIDS, 2006). As the working-age adults fall ill and die, HIV affected households are reported to experience a decrease in household income, health and food security (HelpAge International, 2002; UNAIDS, 2006; UNICEF, 2003). Reports by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and HelpAge International suggest that elderly Africans do not have the social and economic resources to care for orphaned grandchildren and are at risk of ill health but few studies have systematically measured and compared the health status of caregivers and non-caregiving peers (HelpAge International, 2002; UNAIDS, 2006; UNICEF, 2003).

The Kenyan Grandparents Study is longitudinal study conducted in Nyanza Province Kenya which began in 2003. Nyanza Province in Western Kenya has a prevalence rate which ranks among the highest on the continent (UNAIDS, 2006). An estimated 30-39% of adults living in Nyanza Province are infected with HIV with no signs of a decrease in prevalence in the near future (Nyambedha et al., 2001; UNAIDS, 2006). While exact numbers have not been published, a large portion of the 1.1 million orphans of Kenya reside in Nyanza Province (Nyambedha et al., 2003a; UNAIDS, 2006; UNAIDS/UNICEF/WHO, 2002). Luo are the third largest ethnic group in Kenya and the primary inhabitants of Nyanza Province in Western Kenya (National Council for Population and Development, 1999). Luo are primarily subsistence farmers and pastoralists with some additional income based on fishing, small scale gold mining and migrant work (Nyambedha et al., 2001; Ochieng’, 1985; Ocholla-Ayayo, 1999).

In 2003, 200 Luo grandparents, half caregivers and half non-caregivers were recruited and series of data were collected including: anthropometrics, health status, perceived stress and salivary cortisol. In 2003 and 2004, caregiving grandmothers were found to have lower fat reserves than non-caregiving grandmothers whereas caregiving grandfather’s were found to be relatively advantaged nutritionally. In 2005, with an NSF grant, the PI expanded the
evaluation of nutritional status, gender and caregiving in a larger sample that covered a wider geographical area. In addition the data listed above, additional data on food intake, energy expenditure and food distribution were collected from 2005-2007. Data collected in these later years, suggest that generally there are few differences between caregivers and non-caregivers and where there are differences, caregiving grandmothers appear to be advantaged. They generally have greater fat reserves and food intake. While female caregivers have greater energy expenditure, energy expenditure declines among caregivers as the number of orphans under their care increases. The results from these later studies suggest that orphans in the homestead may present an adaptive advantage to grandmother’s in a community in which women have few resources.

This paper will explore the factors which contribute to differentials in nutritional status among Luo grandparents. In addition, it discuss the discrepancies between the earlier and later data of this project. There are several possible explanations of the discrepancies between the earlier and later studies including, sample differences and historical events that will also be explored in this paper. The paper will also discuss why the results from this project are contrary to other studies in Africa, many of which have reported that grandparent caregivers are suffering ill-health as a result of their role. While some of the difference in findings may be a result of different methodologies, other context variables are likely important. Finally, this paper will discuss the implications of such findings for elder care policies in Western Kenya.

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Pranitha Maharaj

Background: South Africa has one of the most rapidly ageing populations in Africa with more than one in eight persons aged 50 and over and nearly 7 percent aged 60 and over (Kinsella and Ferreira 1997). The impact of the AIDS epidemic on the population aged 50 and over is likely to be substantial. The implications of caring on the older population are likely to be economic, emotional and physical. Thus far, however, the story of older men and women caring for the sick and dying as well as orphans has largely gone untold. This study hopes to address this gap by trying to understand the impact of AIDS on older men and women who are caregivers to their partners, children and grandchildren. The overall aim of the paper is to understand the multiple impacts of AIDS on older men and women.

Method: The study was conducted in one urban and one rural site in KwaZulu Natal – the province with the highest prevalence of HIV/AIDS in South Africa. A combination of qualitative and quantitative methods was used. The quantitative data was derived from a cross-sectional survey and the qualitative data was derived from focus group discussions.

Results: Almost 17% of respondents reported in the survey that they had ever cared for someone who was living with HIV/AIDS. In most cases, this was a child or relative. Only 7% of respondents reported that they were caring for any children orphaned due to HIV/AIDS. The results from the focus group discussions and survey suggest that the burden is greater for women than men. Almost 50% of the respondents who had ever cared for someone who was living with HIV/AIDS perceived themselves at medium or high risk of HIV infection because of their caregiving activities. It is clear from the focus group discussion and survey that there is still
some gaps in knowledge about the means of protect themselves but there also other factors that prevent them from taking appropriate measures to reduce their risk of HIV infection. Many older men and women are struggling to meet the demands placed on them and therefore face huge risks to their own health and economic well-being as a result of their caregiving activities. The burden of providing care in the midst of high levels of poverty becomes too great for many of them who report physical exhaustion and despair at their situation. In the survey, 58% of respondents who were caring for someone living with HIV/AIDS reported that they experienced emotional or psychological fatigue due to their caregiving activities. The majority of older men and women in South Africa are dependant on pension funds which provide support not only for themselves, but also other members of the household as well. Many older men and women often find themselves going into debt as a result of their caregiving responsibilities. Sometimes they are forced to depend on their neighbours and community members for assistance. However, there is also a stigma that is attached to caring for someone who is living with HIV/AIDS. Some of the men and women reported that they experienced negative reactions from members of the community. In the survey, 42% of those who were caring for someone living with HIV/AIDS reported experiencing some stigma. Importantly, 15% of those who were caring for someone living with HIV/AIDS reported experiencing violence. However, there were also some indications that attitudes to people living with HIV/AIDS are changing. It became clear in the focus group discussions that for some men and women, neighbours are a very valuable source of support.

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The Impact of Adult Deaths on the Elderly in Tanzania

Achyuta Adhvaryu & Kathleen Beegle

We contribute to the understanding of the impacts of HIV/AIDS-related mortality by analyzing the impacts of adult deaths on the labor supply and health outcomes of individuals above 50 years old in the Kagera region of Tanzania. We find that the change in farm labor supply for these individuals shows no response to an adult death in the household in the last four years, but increases by about 4 hours per week five to eight years after an adult death, and about 6 hours per week nine to thirteen years after an adult death. Labor supply for elderly women changes more in response to adult death than for elderly men. The labor increases are greater for adults who died between ages 15 and 29 compared to ages 30 to 50. We find evidence that livestock assets play a role in mitigating the increase in labor supply. Last, we find that changes over time in health outcomes among these elderly are unaffected by adult death, while individuals with an adult death in the past four years actually experience a greater than average change in log food consumption. Our findings are robust to re-weighting to account for attrition bias and to the inclusion of a history of crop and illness shocks.

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Headship of Older Persons in the Context of HIV/AIDS in Rural South Africa

Enid Schatz and Sangeetha Madhavan
This paper examines older persons’ living arrangements in the Agincourt sub-district of Mpumalanga Province, South Africa—an area with 32% HIV-prevalence. We examine the likelihood of an older person being the household-head across household-level death-status categories for deaths occurring in the 2000-2005 period. In addition, we investigate differences in older persons’ transitioning into the household-head position over this 5-year period across households with an HIV/AIDS, other or no death over the period. Using cross-sections of the Agincourt Health and Demographic Surveillance System data, we conduct logistic regression analysis (1) at the household-level to assess the odds of a woman 60+ or a man 65+ being household-head in 2005 by household mortality experience (2000-05), and (2) at the individual-level to estimate the likelihood of an older person, who was not a household head in 2000, becoming household head by 2005, first by household mortality experience, then by cause of death.

Socio-Economic Differentials Between HIV-Caregivers and Non-Caregivers: A Case of Older People in Nairobi City’s Slums

Gloria Chepungen Langat, Jane Falkingham, Nyovani Madise and Maria Evandrou

Introduction: Providing care to someone with a chronic illness including HIV/AIDS results in additional financial costs on the caregiver which can lead to negative economic consequences. Direct costs arise from expenditure on goods and services relating to care and indirect costs are associated with income forfeited by the care recipient or the caregiver through loss of employment or reduced productivity causing financial strain on the caregiver. This paper seeks to investigate the association between care-giving to someone with a HIV-related illness and the socio-economic status of their caregiver. Older people living in these slums, already disadvantaged due to the changing structure and function of the family and their diminishing capacity to engage in income generation resulting from both physical inability and lack of relevant skills in a changing labour market with no social protection to fall back to, face additional challenges from HIV/AIDS.

Design and Methods: Using cross-sectional survey data collected from 2,771 older men and women aged 50 years and older living in the slums, this paper compared the socio-economic status of older people providing care to someone with HIV/AIDS-related illness with two comparison groups. The paper also makes a methodological contribution to the study of HIV/AIDS impact through use of comparative analysis. The data is complemented with qualitative in-depth interviews data with 30 caregivers.

Results: Findings indicate significant differences in living arrangements, wealth, income and expenditure between caregivers and non-caregivers. HIV-caregivers were found to live in larger households and were also more likely to live in households with a large number of children below the age of 15 years. Whereas a high proportion of HIV-caregivers are ranked highly in terms of wealth status, differences in per capita income and expenditure were not significant.
when household size and other factors are accounted for. Another key finding was that a higher proportion of HIV-caregivers rely on salaries as their main source of income compared with the comparison groups.

**Conclusion:** Older people providing care may in the immediate and longer term be economically disadvantaged due to their large number of dependents. Reliance on salaries is not sustainable given the challenges older people face in their attempt to continue participating in the labour market. They are therefore at an insecure position especially in urban areas where labour-force participation is crucial for survival. Majority of the older people do not have access to pension or formal social security support therefore the ability to earn an income is crucial in avoiding falling into destitution.

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**The Dangers of Losing Strength:**
The Consequences of Physical Ageing for Older People’s Care and Support Relations in the Era of AIDS, Northwest Tanzania.

*Josien de Klerk*

This article describes the role of ageing bodies of older people (above 60) in giving and receiving care in the context of AIDS in northwest Tanzania. The death of prime-aged adults from AIDS requires an increased care giving role, both active care for dying patients and increasing responsibilities in raising grandchildren. The changes in family care relations as a result from AIDS death also requires an active role of older people in negotiating care and support relations for their own care in old age. Data collection for this ethnographic study comprised a combination of semi-structured interviews with all older men and women above 60 living in one sub-village, and the longitudinal following of eleven older people and their families over the course of several months. Findings indicated that a core challenge for older people in managing changing care relations was the fact that their bodies were ageing. The theme of ‘strength’ and the failing body’ featured in the majority of interviews and conversations. The ageing body as a focus of analysis has been largely absent in discussions about the impact of AIDS on older people. This article attempts to fill that gap by analyzing how strength plays a role in giving and receiving care. The able body is a necessity for building relations, through working together, through providing for dependents and through socializing in religious meetings and daily visits. When bodies age, older people become more and more dependent on these relations. A decrease of strength in the context of AIDS often leads to insecurity in advanced old age and sometimes even early death.

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**Caregiving in the Context of HIV/AIDS: Perceptions of Kenyan grandparents of Orphans**

*Sharon V. King, Candace L. Kemp, Eunice Owino, Sister Paul Anastasia*

The rapidly growing body of research about older people in Africa largely results from the unprecedented, continent-wide impact of HIV/AIDS. The demise of millions of middle-
generation adults in African families has left older relatives as the primary source of support for many orphans and vulnerable children (OVCs). As aging specialists, health workers, and government policy makers strive to identify the most appropriate and effective responses to the daunting challenges many of these caregivers face, the perspectives of older caregivers about their unanticipated roles as heads of HIV/AIDS-affected households are gaining greater attention. HelpAge International, a 52-country NGO that addresses the needs of older adults, asserts that the United Nation’s Millennium Goal to halt and reverse the effects of HIV/AIDS by 2015 is reachable only if the views of older caregivers are included in the program planning (HAI, 2007). The purpose of this paper is to describe older Kenyan caregivers’ perceptions of their caregiving activities, challenges, and informational needs, along with the service implications of the findings. Qualitative data were collected with a survey instrument from a purposive sample of 205 grandparent caregivers, identified and interviewed by the staff of the Ahero Old People’s Project in Nyanza province, Kenya, a community-based organization supported in part by Help the Aged Canada. Caregivers in the sample ranged in age from 50-87, with 87% female, and a mean number of 3.21 orphans in their care. Content analysis was conducted to identify key themes of caregivers’ responses to questions about their knowledge of HIV/AIDS, their caregiving experiences, and their recommendations for support services. Analysis suggests that these caregivers have limited HIV/AIDS knowledge but are eager to learn and seek to increase their caregiving capacity. They have concerns about communal well-being, as well as their individual needs, and they recognize the importance of advocacy. Recommendations to strengthen the caregiving capacity of older African caregivers, including those reported by the survey participants, are offered.

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Household Size and Composition During the AIDS epidemic in rural Uganda – What Implications for Older People’s Well-Being?

Janet Seeley

The impact of HIV and AIDS on older people is often portrayed as bound up in the care of children left in their charge when parents die. The impact on older people’s own care and general well-being as they age is less often explored. This paper will focus on the size and composition of households with older people (over 60 years of age) in a rural area in Uganda and examine the impact of HIV and AIDS on their care and support. The MRC/UVRI Research Unit on AIDS has since 1989/1990 collected demographic data from a population cohort of 20,000 people in South-West Uganda. Data on socio-economic status, based on an asset-index, are collected every 4 years and households are classified into 3 groupings: poor, less-poor and rich. The data available at the moment show that among the cohort 3% (627) of people were aged over 70 in 2006, 13% of whom were living alone. Of the 13%, half was classified as poor in 2006/2007.

We will combine the quantitative analysis of the survey data with longitudinal data from ethnographic studies in 1991/1992 and 2006/2007 with 26 households drawn from the larger cohort representing different household types and socio-economic ranks. Our findings from the qualitative research show the importance of socio-economic status and family size, as well as
some measure of good fortune in sustained health, in mitigating the impact of the epidemic for the old. We will explore these factors through the survey data.

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HIV/AIDS in China: The impact on older adult caregivers and their families
Karen I. Fredriksen Goldsen, Cheng-Shi Shiu, Helene Starks, Wei-Ti Chen, Jane Simoni, Cynthia Pearson, Hongxin Zhao, and Fujie Zhang

China is experiencing a rapid increase in the number of HIV/AIDS infections. It is estimated that more than 700,000 people are currently living with HIV in China (Zhang, 2007). Without the implementation of comprehensive prevention and treatment efforts, it is estimated that the number of cases will continue to rise dramatically and that by 2010 the number of persons in China with HIV will reach more than ten million (Center for Strategic and International Studies, 2003). Based on a survey of 120 persons living with HIV/AIDS in China and in-depth qualitative interviews with 12 family caregivers, this paper explores the needs and experiences of older adults providing care to family members living with HIV/AIDS. This paper examines the type and extent of assistance provided, and the ways that older adult caregivers support adherence to antiretroviral medications and treatment. The majority of older adult caregivers report severe distress, including financial hardship, social isolation, physical and mental strain, and constant worry about the future. As a family-oriented society, utilizing family caregiving support is likely an effective strategy to support persons living with HIV/AIDS in China; however, the stigma and shame associated with HIV/AIDS create tremendous distress for older family caregivers and may create strain within familial relations. While cultural values sanction family caregiving roles, the interplay between stigma and cultural values must be considered.

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Community Reaction to Older-age Parental AIDS Caregivers: Evidence from Cambodia
John Knodel, Kiry Sovan Kim, Sina Puch, Chanpen Saengtienchai, and Nathalie Williams

Accounts of community reaction to persons with HIV/AIDS and their families typically emphasize negative aspects and stress forms of stigma experienced. There is often little recognition that the situation is likely to vary substantially over time and across settings. In addition evidence presented is often anecdotal or based on questioning that only inquire about negative reactions. Our paper we will examine community reaction in Cambodia to families in which an adult either died of AIDS or is HIV infected and currently under treatment with an emphasis on their parents experience, many of whom are older age. Our analysis will be based on both quantitative data from survey interviews in 2004 and 2005 with over 100 older age parents of adults who died of AIDS and 25 open-ended interviews in 2006 with older age parents who had an adult child either who died of AIDS related illnesses or was currently being treated for HIV/AIDS. Both sources covered positive and negative reactions. The results reveal a far more varied situation than most portrayals of the situation in the international literature provide and suggest significant improvement in reactions over time.

More specifically we will examine social contact (visiting, avoidance) during illness and recovery (in cases on ART), at funerals and following the death of an adult child from HIV/AIDS; reactions to grandchildren; positive reactions such as expressions of concern and sympathy or assistance from others in community (food, money); gossip; effects on livelihood;
and how families coped with negative reaction. In addition we will consider how the situation has likely changed over time and likely reasons for it.

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The Impact of AIDS on Intergenerational Transfers in South Africa: Evidence from the Cape Area Panel Study

_Cally Ardington, Anne Case, David Lam, Murray Leibbrandt, Alicia Menendez, and Analia Olgiati_

The HIV and AIDS crisis in sub-Saharan Africa has resulted in the deaths of a large number of prime-aged men and women, leaving a generation of children in need of non-parental care. Recent research has focused on educational and health outcomes for children absorbed into non-parental households, generally headed by kin. Less empirical work has explored how decisions are made on who will house and raise orphaned children, and the extent to which kin, non-resident with the orphans, contribute to the expenses associated with child-rearing. In this paper, we use panel data collected in metropolitan Cape Town to document the role played by aging parents in caring for the children of children who die. In addition, we quantify the probabilities that older adults and the older adults' children provide time and money to orphaned grandchildren.

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The Effects of the AIDS Epidemic on the Elderly in a High-Prevalence Setting in Sub-Saharan Africa

_Philip Anglewicz, Jere R. Behrman, Peter Fleming, Hans-Peter Kohler, Susan Watkins and Winford Masanjala_

This presentation will provide preliminary tabulations from survey data collected in rural Malawi May-August 2008, augmented by qualitative data. The elderly sample consists of (i) elderly respondents in the core sample of the longitudinal Malawi Diffusion and Ideational Change Project; ii) elderly parents of younger adults in the MDICP, both those who live in the same compound as the younger-adult respondents; and non-resident respondents who will be tracked in order to take the selectivity of residential arrangements into account. The tabulations will include basic characteristics of the both adult children and the elderly (e.g. living arrangements, HIV status, health status as self-reported and using anthropometrics) and, for a subsample, biomarkers of other health conditions, as well as tabulations of both intra-familial and inter-familial transfers of money, goods and time.

We also expect to be able to address aspects of the overall aim of this study: to examine the effects of adult children’s HIV status (both perceived and by serostatus) on intrafamilial exchanges and on the residential arrangements and health of the elderly. For example, are there variations by gender? Is HIV status associated with substitution in intergenerational transfers, e.g. from aging parents to siblings and children? Are these affected by previous “investments” of aging parents in their adult children, e.g. through their schooling? And how do intergenerational transfers associated with AIDS morbidity and mortality compare with other shocks, such as severe food deficits?
Intergenerational Relationships of HIV-Infected Patients in the Antiretroviral Era: Patients’ Perspectives in Northern Thailand

Sophie Le Coeur, Eva Lelièvre

Thailand was the first Asian country affected by the AIDS epidemic in the late 1980s, and one of the hardest hit: among its 64 million inhabitants, nearly one million people are estimated to have been infected.

Families have been considerably affected emotionally and economically by the disease, which preferentially strikes young adults, who are sometimes already parents themselves. Previous studies of its impact on intergenerational relationships were mainly undertaken before treatments became available. However, with the new availability of antiretrovirals which have transformed HIV infection from a lethal to a chronic disease, it is crucial to re-examine the interaction between parents and their adult HIV-infected children.

The objective of our paper is to examine intergenerational relationships within HIV affected families in the era of generalized antiretrovirals access. On the one hand, what do HIV-infected adult children get from staying with their parents: a family? a place to stay? a place where they feel secure with regard to their HIV status? a place where they get financial support? emotional support? care? child care for their own children? On the other hand, to what extent are adult HIV-infected children providing financial support to their parents, as is culturally desirable in Thailand?

The “Living with Antiretrovirals” (LIWA) study\(^1\) aims at evaluating the socio-demographic and economic impact of access to antiretroviral treatments in a community severely affected by HIV. A quantitative life-event history survey of all adult patients (n=513) currently receiving antiretroviral therapy, including face-to-face interviews, was undertaken in four community hospitals in northern Thailand in 2007.

Focusing on the families of patients who still have at least one parent alive, we use this rich dataset to analyze the intergenerational relationships between patients and their relatives. According to their living arrangements at the time of the survey, we explore a range of behavior differentials. The data collected include (1) socio-demographic characteristics such as sex, age, marital status, number of children; (2) household size and composition; (3) education; (4) financial situation; (5) disease and health history; (6) sources of support in case of crisis. Among the patients interviewed who still had at least one parent alive (three-quarters of the sample), one half were living with their parent(s). While parents are clearly a significant source of support for their adult children, whether or not they live together, there is evidence of reciprocity. For example, among patients living with their parents, one-third own the house where they live together. As usually observed in most societies, patients with their own families are less likely to live with their parents. While emotional support from parents is preferentially offered within the household, financial support is provided irrespective of co-residence status.

\(^1\) Funded by the ANRS (grant 12 141)
The prospects of the patients under antiretrovirals have radically changed and this plays a major role in shaping their relationship with their parents. Their regained health allows them to work, take care of their family and fulfill their filial duties as expected in the society.

A survey is currently being undertaken among a control group in the general population. Some comparative elements will be available at the time of the conference.