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# Children as caregivers of older relatives living with HIV and AIDS in Nyang'oma division of western Kenya

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There is growing debate about the situations of children who care for a relative with HIV-related illness, especially in developing countries with high HIV prevalence. In particular, there is inadequate information on the long-term consequences of children taking on this caregiving role. The article reanalyses data collected between January and November 2006 in a rural setting in western Kenya where 19 children caring for a total of 15 people living with HIV or AIDS (PLHIV) participated. Data were collected through in-depth interviews, participant observation, focus group discussions and narratives. The findings show that children regularly become involved in caregiving due to lack of a responsible adult to perform the role, which may be as a result of HIV stigma and rejection of the care recipient by extended family members and neighbours or because of cultural barriers. Fulfilling the responsibilities of caregiving had profound repercussions for the children's lives, including psychological distress, physical burden, dropping out of school, participation in wage labour, and forced early marriage. Financial needs pushed some girls into transactional sexual relations, predisposing them to the risks of unwanted pregnancy or sexually transmitted infections. Since the children providing care for PLHIV are themselves vulnerable, we recommend that they should be targeted with support.

**Keywords:** carers, families, home-based care, qualitative research, resource-poor settings, social aspects, sub-Saharan Africa

## Introduction

In the context of the HIV epidemic in sub-Saharan Africa, increasingly more studies have focused on the vulnerability of children — but mainly in terms of orphanhood, the related inadequate levels of support for children affected by HIV or AIDS, and the resultant increase in child labour (see UNICEF, 2003; Adato, Kadiyala, Roopnaraine, Biermay-Jenzano & Norman, 2005; Nyambedha, 2006; Nyambedha & Aagaard-Hansen, 2010). However, the role of young children as caregivers to a family member with HIV or AIDS has received less attention (Robson, Ansell, Huber, Gould & Van-Blerk, 2006; Becker, 2007). Becker (2007) states that in every group of 100 children in the United Kingdom, Australia or the United States, as many as four children may be fulfilling a caregiver's role. In Africa, the total number of child caregivers is likely to be in the millions because of the large number of people living with HIV or AIDS (PLHIV). This situation has also been compounded by the policy of home-based care for PLHIV, introduced after it was realised that a large number of HIV-infected persons had overstretched healthcare facilities and increased healthcare expenses (National AIDS and STI Control Programme [NASCOP] & Ministry of Health (MoH), 2002; World Health Organization, 2002). In Africa, most PLHIV remain at home where they are cared for by a close

relative, thus making even young people possible caregivers (Robson, 2004; Evans & Becker, 2009).

In Kenya, sexually active females in the age group 15–49 years have been heavily affected by the HIV epidemic (Central Bureau of Statistics, Ministry of Health [MoH] & ORC Macro, 2004; National AIDS and STI Control Programme [NASCOP] & MoH, 2008; UNAIDS, 2009). By virtue of their age, this highly affected group may not have adult offspring to rely on if they require care. Even when there are adult relatives living nearby or in the households with PLHIV, they may be unwilling to provide care due to HIV stigma (Parker & Aggleton, 2002; UNAIDS, 2007). Evans & Becker (2009) argue that despite the highly acknowledged home-based care provided by family members of PLHIV, what the family members choose to do in terms of caregiving depends on the existing socio-cultural, economic and policy environment. Apart from HIV stigma and discrimination, other local particularities such as gender roles and cultural norms may impede caregiving among relatives. Therefore, it is important to understand the context in which children are left to assume these caregiving responsibilities.

Recent literature (e.g. Robson *et al.*, 2006; Skovdal, Ogutu, Aoro & Campbell, 2009; Evans, & Becker, 2009; Abebe, 2010; Evans, 2010) has shown that children view

their participation in HIV-related caregiving in a positive light — particularly as something enhancing their close relationship with the recipient, and as a sign of maturity or being a responsible family member. However, the negative effects of the caregiving process on the lives of children in the long term — as was anticipated by NASCOP (1998) and UNAIDS (2000) — are not yet fully understood. In a Tanzanian study, Robson *et al.* (2006) explains that caregiving often caused children's irregular school attendance, without necessarily dropping out. In contrast, in a similar study in Zimbabwe, Robson (2004) observed that children dropped out of school due to caregiving. In Kenya, a policy stipulating free primary school education (implemented in 2003) led to increased enrolment of school-aged children, from 77.3% in 2002 to 92.5% in 2008, and primary-school completion increased from 62.7% in 2003 to 81% in 2007, with a slight decline to 79.5% in 2008 (UNESCO, 2010). However, a significant number of children do not benefit from the policy (UNESCO, 2010) and the reasons why vulnerable children are not in school have not been fully established.

Children providing care have been observed elsewhere to contribute to the financial sustainability of the families in which they live (Becker, 2007; Skovdal, 2010; Abebe, 2010). A study on orphans and vulnerable children in western Kenya revealed that, in certain instances, children's involvement in income-generating activities can have negative consequences on their overall growth and development (Nyambedha & Aagaard-Hansen, 2010). In contrast, little is known about the consequences of children's caregiving role on their overall growth and development, particularly in those regions worst affected by HIV and AIDS.

### Study setting

The study was conducted in Nyang'oma division, Bondo district, in western Kenya. Nyang'oma is situated along the shores of Lake Victoria and is inhabited mostly by the Luo, a patrilineal community that mainly practices subsistence farming, fishing and small-scale gold prospecting (Nyambedha, 2000). The area receives unreliable rainfall and is food insecure (Republic of Kenya, 2002).

The Luo community has been adversely affected by HIV and AIDS, with HIV prevalence estimated at 17.5% for men and 25.8% for women, against the national average of 6.7% (4.6% for men and 8.7% for women) (CBS, MoH & ORC Macro, 2004). Several reasons have been advanced to explain the high prevalence of HIV and AIDS in the community, including the frequency of widow inheritance (Prince, 2004) and the *jaboya* system wherein women who market fish offer sex to the men who catch the fish (Odek, 2007; Kwena, Bukusi, Omondi, Musa Ng'ayo & Holmes, 2012). Other factors contributing to higher HIV prevalence in the community include that Luo males are not circumcised (Kenya National Bureau of Statistics [KNBS] & ICF Macro, 2010) and HIV transmission as the result of the higher-risk sexual activities of long-distance truck drivers along the northern corridor. The northern corridor passes through the Luo community where long-distance truck crews may find temporary lodging as they transport goods and petroleum products from the port of Mombasa to the

landlocked countries of East Africa (Republic of Kenya & United Nations Development Programme (UNDP), 1999).

In line with the national policy (see NASCOP & MoH, 2002), home-based care for PLHIV is practiced in the study area (Olang'o, 2008). By 2006, a total of 405 PLHIV had registered for antiretroviral treatment (ART) at two local health facilities in Nyang'oma division (Olang'o, 2008). Since then, the number of PLHIV on ART receiving home-based care has certainly increased because of high HIV incidence and due to the national rollout of ART. The Ministry of Health and some nongovernmental organisations (NGOs) collaborate with community health workers (CHWs) to support PLHIV (NASCOP & MoH, 2002). Organisations such as the Centers for Disease Control and Prevention (CDC), Mildmay International and the St Francis Community Development Programme (FRACODEP), among others, also operate in the area (Olang'o, 2008). These organisations have recruited and trained CHWs on the management of opportunistic infections and the referral system for complicated cases. However, a recent study revealed a high rate of staff attrition from the home-based care programme (Olang'o, Nyamongo & Aagaard-Hansen, 2010); this may eventually leave the children who fulfil a caregiving role without any external support.

Cultural norms in the Luo community may also impede adult relatives from providing care to PLHIV, thus throwing the burden onto children. In the study area, parents, married sons and daughters-in-law are prohibited from entering each other's bedroom or having physical contact even if to provide nursing care. It is generally believed that violating this norm causes *chira* ('wasting illness') (Prince, 2004). In such circumstances children are considered 'neutral' and are allowed to provide nursing care, although gender-related factors could mean that girls perform more caregiving duties than boys (UNAIDS, 2000).

In the past, Luo cultural norms did not allow a boy to do household tasks, such as cooking, washing or fetching firewood and water, all of which were considered female duties. However, Skovdal *et al.* (2009) shows that both boys and girls in the Luo community may now participate in caring for sick relatives. As described by Skovdal *et al.* (2009), boys may take up caregiving responsibilities not only because of circumstances (for example, the absence of any female in the household), but also as a socialisation strategy to prepare them for the future possibility of caring for their own partially orphaned children or an ill spouse. In that context there is also a need to show the influence of gender in children's participation in caregiving for PLHIV.

### Methods

#### Data collection

This article presents a reanalysis of data from an 11-month project called 'An ethnographic study of home-based care for people living with HIV and AIDS in Nyang'oma division, Bondo district of western Kenya,' which was conducted between January and November 2006. The informants were selected through purposive and snowball techniques, particularly through community health workers (CHWs), local NGOs and health facilities.

A total of 19 children and the 15 PLHIV whom they cared for were interviewed in-depth to determine how the children came into their caregiving role, the kinds of caregiving duties they performed, the sources of their support, and the problems they faced (such as psychological distress and keeping up with school attendance). The children were also given notebooks for writing personal narratives about their experiences with caregiving responsibilities.

Ten of the 15 PLHIV were linked with a total of six CHWs, while the rest did not link with any CHW. The six CHWs as well as four NGO staff members and five health-care officials were interviewed as key informants to give background information on any external support, counselling or caregiving training offered to the child caregivers.

Two focus group discussions (FGDs) were conducted, one each with the participating PLHIV and CHWs, to validate data emerging from the in-depth and key informant interviews. There were six participants in each focus group, which lasted one hour and were moderated by the principal investigator. The discussions were tape-recorded and notes were taken.

Long-term follow-up was initiated soon after initial contact with the participants and the families were visited on a monthly basis over the entire study period. In-depth interviews and ethnographic methods of participant observation were used to observe the dynamics of the caregiving process.

### Data analysis

The data were analysed using ethnographic techniques. This mainly involved content analysis, where the recorded interviews were studied to identify relevant themes which then formed the basis for discussions about the children's involvement in caregiving and the challenges they faced. These analytic themes are illustrated through selected comments from the child caregivers, care recipients and CHWs.

### Ethical considerations

The study was approved by the University of Nairobi, and a research permit was sought from the Ministry of Higher Education, Science and Technology. Informed consent was obtained from all participants, including the children and their parents, as recommended by the National Children's Bureau (2003) and Ritchie & Lewis (2003) and consistent with Article 12 of the United Nations Convention on the Rights of the Child. Given that about two-thirds of the care recipients had not disclosed their HIV-positive status to their child caregiver, caution was exercised when interviewing the children to avoid asking questions that would directly touch on the HIV status of their care recipient to prevent evoking distress.

Although it is unethical to give financial benefits to study participants (see Ritchie & Lewis, 2003), it was very difficult to decline the children's requests for money to buy food or school items. We considered the moral negotiations and emergent ethics which depend on the situation at hand (see Pels, 1999), and in most cases avoided direct monetary assistance and instead would buy food items ourselves or else pay family medical bills at the local health facilities.

The principles of confidentiality and anonymity were observed. Information given by the participants was kept confidential, and the names used here are pseudonyms.

## Findings

### Sociodemographic characteristics of the child caregivers and care recipients

A total of 19 children (7 boys and 12 girls), ranging in age from 10 to 18 years, were providing care to a person with HIV. Seventeen were the child of the ailing care recipient, while the remaining two were a 12-year-old girl sent from a neighbouring division to care for her ailing older sister, and a 16-year-old daughter-in-law who was married to a 17-year-old male to provide supportive care to his mother.

Fourteen of the 15 PLHIV in the study (13 women and one man) were widowed and one woman was still married. The ages of the care recipients ranged from 25 to 65 years. Four of the care recipients each had two children as caregivers, while the rest each had one child caregiver.

### Reasons why children become the principal caregiver

#### Lack of a responsible adult person in the household

Fourteen of the 15 PLHIV did not have any other adult person in their households. As noted earlier, all but one care recipient were widowed. The one married PLHIV in the study had a husband, but he worked away from home (in Mombasa). Only four of the care recipients had an adult daughter or son; however, the daughters were married and lived elsewhere, and the sons were working in different towns and could only manage to remit money to support the families. The married daughters sometimes visited for a few days at a time before returning to their marital homes. All these circumstances forced the young children whom the PLHIV were living with to assume the responsibility of caregiving.

#### Stigma and rejection

Traditionally, in the absence of another adult person in the household of a PLHIV, extended family members would be expected to step in to care for the ailing person. However, stigma consistently stood as an impediment to giving care:

*'The issue of this disease of today [HIV and AIDS] is very complex, such that if you don't have blood relatives [i.e. a child, parent, sibling] then you just die without anybody coming to see you'* (FGD with CHWs).

*'You ail for a long time until people dislike you. My sister-in-law told me in the face that she fears me. I look awful. She doesn't know even how to greet me. People have no hope once this disease attacks you.... They also think that they can get infected when they come in contact with you. Therefore, I just struggle here, relying on my son and my sister who is married nearby'* (Atieno, a 45-year-old female).

*'I used to live with my paternal uncle after my father's death. When I became sick and disclosed to him my HIV status, he rejected me saying I have been morally loose. Now, my son [age 10] is the one helping me. Occasionally, a community health*

*worker visits me'* (Oduma, a 36-year-old widowed male).

The perceived complexity of HIV and AIDS as phrased in these three excerpts captures the perceived fatalness of the disease, fears of contagion, generalised rejection and other social dilemmas facing PLHIV. It appeared that the relatives of an ailing person would lose hope because of the chronic nature of the disease, while some feared they could contract HIV by being in contact with the sick person, and others believed that an HIV-infected person deserved no support because they had led an immoral life.

#### *Cultural norms about contact and burial*

In some situations, children may end up as primary caregivers due to cultural norms. For example, Kerina, an HIV-infected widow, had an adult daughter-in-law; but the daughter-in-law did not provide her with physical care out of a belief that *chira* would affect her if she entered her mother-in-law's bedroom to bathe her. Instead, she helped with other chores, such as fetching water, and left the primary care duties to Kerina's 12-year-old daughter. Three other PLHIV who lived with their mothers-in-law also faced the predicament of contact avoidance and the other adults' fear of *chira*. Thus, the mothers-in-law would just cook food and then hand it to the children to pass on to their ailing mothers.

In contrast, Atieno, an HIV-infected widow, allowed her daughter-in-law to care for her, arguing that she had *'done away with men.'* That is, Atieno had disengaged from sex and was no longer interested in getting another man to inherit her. (As reiterated by the CHWs, only those still sexually active could face *chira*.)

Burial practices also complicated the provision care to certain PLHIV. For instance, five of the care recipients had gone to their maternal relatives to seek care but were turned away because of the relatives' fear of the financial burden that would be created by transporting the body back home for burial should the ailing person die. Luo custom requires a married woman to be buried beside her own house. The CHWs explained that relatives might also worry that the body of a deceased woman could be rejected by her husband's kin; although they cited instances of this within the community, the situation was not observed among the participants.

#### **Caregiving responsibilities**

The child caregivers performed all the essential care duties, including bathing the sick person, feeding them, giving medicine, cooking, washing clothes, and even providing emotional support. The following interview highlights the extent of their caregiving role:

Caren (age 14): *My mother has been ill for a long time and I'm the one who has been taking care of her. I wash her clothes, bathe her, cook and fetch water, and take care of younger siblings.*

Researcher: *Any other duties that you do?*

Caren: *I give her drugs and even spoon feed her because there are times she can't eat alone. Sometimes she cries a lot and refuses to take medicine.*

Researcher: *What do you do when she refuses to take medicine?*

Caren: *I just console and plead with her to eat or take medicine.*

All the children performed similar duties; except in three households where there were both girls and boys, the girls did nursing care while the boys often dealt with transporting the sick person to the local health facility and looking for income.

The child caregivers received only occasional support from CHWs. Only 10 of the care recipients were linked with a CHW, who might help to bathe and feed the care recipient, clean bedsores or carry food. Relatives, particularly siblings and maternal relatives, sometimes gave the children food and emotional support. The maternal relatives included grandmothers, uncles and aunts, although they mostly lived far from the child caregivers and care recipients.

#### **Problems facing the child caregivers**

##### *Psychological distress*

Five of the 15 care recipients had disclosed their HIV-positive status to the child caregiver. Their reasons for disclosure were because the child could remind them to take their ARV medication or because the child had frequently questioned them about their ill health. However, HIV-status disclosure by the care recipient had caused psychological distress to the child caregivers. Osanya, age 14, was one example. His father and siblings had died, and he often asked his mother where he could go to live and continue with his education if she too died. He revealed his anxiety to us and constantly asked whether his mother's health would improve; over the period of study, his mother's health did improve and his anxiety subsided.

However, children who did not know the HIV-positive status of their care recipient were not spared from psychological distress. Most often their distress emanated from taking care of a parent and witnessing their pain:

*'It is just painful taking care of your own parent. Sometimes you see her seriously ill, crying in pain, and you are helpless. You just shed tears'* (Akinyi, 14-year-old female).

In certain cases, the children experienced distress when there was no food in the home; consequently, they might find ways to work for people or they would beg from relatives and neighbours who sometimes scorned them:

*'Sometimes you find there is no food in the house; it becomes more stressful imagining how you have to look for a way out. You go to beg from some people and the look that you meet is just awful. When you persistently go to them, some of them tell you to stop bothering them because they didn't make your mother become sick. Their children sneer at you and when we go school they tell other children that you always go to them for food'* (Akinyi, 14-year-old female).

##### *The influence of caregiving on the children's schooling*

Nine of the children (seven in primary school and two in secondary school) had dropped out of school as a result of their caregiving responsibilities (see Table 1). The remaining

10 children attended school occasionally, depending on the condition of the ill person. Two children who were supported by a charity had withdrawn from boarding school, but one managed instead to go to a nearby day-school so she could return home each day after classes to help her mother and younger siblings. Akinyi (age 14) transferred from a distant primary day-school to go to one nearer her home so that she could take care of her ailing mother.

The children attending school often missed lessons, which would have contributed to their poor performance in examinations; eight of these children had repeated a grade since they had taken on their caregiving role. One woman care recipient acknowledged that her 16-year-old son had dropped in his academic performance because he was overburdened:

*'He misses school and takes me to the hospital on a bicycle. Like this week, I have been going to Bondo Hospital daily to take injections. He is the same person who ensures that our few goats and cattle are tethered in the morning. During lunch break, he takes them down to the stream for watering. At 4 p.m. he sneaks back to graze them before darkness. So he is overburdened and can't perform well in class. He ought to have been in secondary school this year, but he repeated class seven, so he will sit national examinations this year'* (Jaber, 38-year-old widowed female).

#### Participation in wage-earning activities

Although other relatives sometimes extended support to the child caregivers, it was often little and unreliable. Moreover, the children received meagre support from the CHWs. This forced the children to participate in wage-earning activities to support their households. Apart from working on family gardens to secure food, they also found jobs, such as charcoal-burning, working on other people's farms, selling cakes, fishing or operating a bicycle taxi (*boda boda*) (see Table 1).

The children who relied on sources of income other than remittances from relatives and older siblings faced various challenges in their endeavours. For example, those doing charcoal-burning were often chased away from other people's land for cutting down trees. One boy who fished spent sleepless nights on the lake, rowing a boat and pulling in fishing nets. A boy who relied on his bicycle taxi for an income strained with heavy loads and often complained of fatigue and an aching body.

**Table 1:** The child caregivers' participation in income-generating activities ( $n = 19$ )

Sources of income	Number of children participating
Charcoal-making	8
Working on farms ( <i>amali</i> )	8
Remittance (e.g. from an older family member)	3
Selling cake	2
Selling fish	1
Selling vegetables	1
Bicycle taxi ( <i>boda boda</i> )	1
Fishing	1

Gender appeared to play a less important role in the children's participation in payable activities, except for *boda boda* and fishing, which only boys took part in. Besides being strenuous, these payable duties in general earned very little income for the children relative to the families' needs. Girls who could not work as vigorously as boys fetched very little income. In the course of providing care, three of the girls had become pregnant. Although none of the girls was free to talk about her pregnancy, their mothers explained that they must have been pushed into sexual relations in exchange for financial favours to meet their basic needs.

#### Forced early marriage

*'I was learning in one school in Kisumu two years ago. So, when my parents fell sick my father called me to return home. I waited and sat my class-7 examination and came in December 2005. One evening dad called me next to his sick bed and told me to look for a lady to marry in order to get somebody who would help me care for my mother. At first, I thought he was joking. The following day he reminded me, and I realised he was serious. I decided to run away to Sirongo beach. He sent an uncle of mine to bring me back. That same week he sent me to my married aunt in Uyoma to bring him medicine. On reaching there, my aunt instead introduced me to a lady whom she wanted me to marry. I had no choice. So, I just gathered courage and talked with her. By that time, my aunt had talked with the lady and her parents. The lady was then pregnant, so she accepted the marriage proposal. The following day we came home. Imagine — one week after my marriage my dad died. Since then my wife and I have been caring for my mother and we are happy. When I am out to do fishing, she is there with my mother. She has been of great help to our family'* (Omoja, 17-year-old male).

This narrative shows how the need to fulfil a caregiving role may force children out of school and into marriage at an early age. The boy's father had foreseen that he would soon die and that his son would have difficulty caring for his mother. In Luo culture, females are expected to provide nursing care to their mothers, while males may bathe their fathers in case there are no female family members to help. Also, the father had anticipated a situation whereby the mother would have no one at home to care for her if the boy went out to look for work. Thus, it became a joint task among the relatives to find someone for the boy to marry. In the end, the 17-year-old appreciated the assistance of his young wife towards the nursing care of his mother when he went out fishing. Likewise, his 16-year-old wife Adero said:

*'People told me a lot of things when my mother-in-law was seriously sick. Some people were telling me that my father-in-law died of HIV and I will also contract it from my mother-in-law when I wash her clothes and bathe her. In fact, I had to change her nappies from time to time because she [had diarrhoea and was] literally attending to all calls of nature in her bed. But I just said to myself that I will not run away because it*

*will look bad and she will also haunt me [laughs].... I said, in future, I may also fall sick and need someone to help me. So, I have persevered, until now she has recovered and everybody can now see. In fact, they appreciate and I feel happy.'*

Despite a lack of support from neighbours and relatives, particularly when she washed her mother-in-law's dirty clothes and bathed her, Adero felt content because she had persevered through difficult tasks until her mother-in-law recovered; this effort as a woman was ultimately appreciated and it earned her a good name in the village.

## Discussion

Several themes emerged from the data, showing how the lives of children as caregivers of PLHIV are affected in their daily activities. This includes how children's education and overall growth can be affected by taking on a caregiving role. Thus, issues concerning children as primary caregivers of PLHIV can be discussed in terms of three main themes: 1) lack of a responsible adult in the household to perform the duties; 2) HIV stigma and rejection of the ailing person; and, 3) cultural barriers to providing an individual with care.

### **Lack of a responsible adult to perform the role**

Many of the PLHIV did not have adult offspring. Among those who had, the adult children themselves were either married or working elsewhere and could not stay with their sick parent at all times. An alternative could have been to seek care in the household of a sister or mother, but these relatives would have feared that their premature death would cause financial burden if they had to transport the body back to their original home for burial. In Luo culture, a married person must be buried next to his or her house (Mboya, 1938; Stamp, 1991; Gelman, 2005). The Luo also believe that when a person dies, the individual's spirit remains active and can cause revenge if the proper mode and place of burial is not followed (Gelman, 2005). As a result of these beliefs, sick individuals are likely to be sent back to their own households to be cared for by their young children, who may necessarily withdraw from school or transfer to a nearby school to succeed in their role as primary caregiver.

### **HIV stigma and rejection**

Stigma is an impediment to the provision of care for PLHIV by their relatives. PLHIV may experience neglect, rejection or withdrawal of support by their family members, including their own partners, leaving them to rely only on young children (UNAIDS, 2000; Parker & Aggleton, 2002; UNAIDS, 2007). The findings concur with Evans & Becker (2009) who argue that what the family members do as caregivers is contingent upon the existing socio-cultural, economic and policy context. However, it is hoped that declining HIV prevalence, universal access to treatment, and improved knowledge of the disease will lessen HIV stigma (Wolfe, Weiser, Leiter, Steward, Percy-de Korte, Phaladze *et al.*, 2008; Kenya National Bureau of Statistics & ICF Macro, 2010). In the meantime, there is still a need for campaigns to reduce HIV stigma and discrimination in society.

### **Cultural barriers**

A cultural belief in *chira* often impeded caregiving by adult relatives in this study. In the Luo community, a mother-in-law and daughter-in-law, for instance, are prohibited from entering each other's bedrooms or seeing the other naked even if to bathe them as a sick individual. Failure to observe the norm is believed to cause *chira*, a slimming illness otherwise believed to be caused by a curse (Mboya, 1938; Prince, 2004). The PLHIV interpreted and responded to this cultural impediment (people's fear of *chira*) in vastly different ways. For example, Kerina recognised that she could not be cared for by her daughter-in-law due to a fear of *chira* and thus enlisted her 12-year-old daughter in providing her care; Atieno avoided this cultural impediment by declaring to her daughter-in-law that she was not sexually active and as such the daughter-in-law would need not fear helping her. In other situations people may engage with notions of religious salvation as a means to circumvent a fear of *chira* (Prince, 2004). However, the study did not investigate the coping strategies among the PLHIV or their relatives.

### **Overarching issues**

A child's gender did not appear to be a barrier to providing caregiving. In the households with only boys, they performed all duties including those typically done only by females, such as cooking, fetching water, washing dirty clothes and bathing the sick. Exceptions were observed in the households with both boys and girls, as the boys shied away from these duties, leaving them for the girls. Thus, it may be argued that the participation of boys and girls in caregiving in the study community is contingent on who is available and less a result of shifts in socialisation as claimed by Skovdal *et al.* (2009).

The children experienced several challenges in the course of their caregiving work, especially coping with psychological distress, dropping out of school, having to look for wage labour, and possible marriage at an early age, all of which go against the United Nations Convention on the Rights of the Child. Specifically, the children caring for a parent who had disclosed their HIV-positive status lived with the fear and trauma of their impending death. Similarly, a lack of food and money to meet other needs also caused the children trauma, as similarly observed among orphaned children in Cape Town, South Africa (Cluver, Gardner & Operario, 2009). In this study, the children's anxiety subsided with time when the health of their parent improved while taking ARVs, which implies that a parent's improved health could renew a sense of hope in the child.

Just over half the child caregivers attended school occasionally, while nearly half had dropped out due to the burden of caregiving and the need to sustain their families by pursuing income-generating activities. Furthermore, the girls were more disadvantaged in terms of finding wage-paying opportunities, with some seemingly having resorted to sexual relations for financial and material gains. For some girls, this had resulted in pregnancy, and was an indicator of the risk of contracting sexually transmitted infection, including HIV. Furthermore, the burden of caregiving was not limited to children with an ailing HIV-infected parent, but

extended to children who had married at an early age to assist in caregiving for an in-law, among others.

Overall, the children approached their caregiving work with agency and resilience despite the challenges they faced. For the most part they maintained a positive view of their role and adjusted to the duties in different ways, which concurs with the findings of studies conducted elsewhere (e.g. Robson *et al.*, 2006; Evans & Becker, 2009; Skovdal & Ogutu, 2009; Skovdal *et al.*, 2009; Abebe, 2010; Evans, 2010). For example, the teenage couple Omoja and his wife, in spite of their early marriage, both expressed happiness with the extent that they had cared for Omoja's mother without support from neighbours and relatives. Omoja's wife cared for her mother-in-law not only out of a fear of being haunted by her if she abandoned her, but she was also driven by the moral principles of perseverance and helping others, which in themselves are appreciated in the Luo community and believed to bring reciprocal benefits, particularly blessings in one's future life.

### Limitations of the study

The findings cannot be generalised beyond the participants due to the purposive sampling method and relatively small sample size. The age of the data is another limitation to interpreting the findings since the study was conducted when ART was being rolled out. With access to ART, many PLHIV can be expected to regain good health, thus children presently taking on a caregiving role may experience fewer problems. The general picture of a child caregiver's reaction towards their care recipient's HIV-positive status was also limited by the fact that mention of the HIV status of the sick individual was intentionally avoided to reduce the possibility of causing distress in the child caregivers.

### Conclusions

This article has shown that children's role in caregiving for PLHIV in this community is largely determined by the lack of a responsible adult willing to provide care within their kin network. Stigma and rejection of PLHIV by relatives and neighbours due to a perception that immoral sexual behaviour has caused their HIV infection, and cultural barriers which do not allow adult females to provide care and support to a parent-in-law (whether female or male) were also noted as compelling children to become a primary caregiver.

Children's participation in caregiving to PLHIV has psychological consequences, interferes with their schooling through absenteeism and poor performance, and increases their chances of dropping out of school or marrying at an early age. Children compelled into a caregiving role will not benefit from the free education programme initiated by the Kenyan government. There is a need to conduct a national situational analysis of children who provide support to PLHIV in order to create measures to avoid or manage the adverse effects felt by the children, and to rather enhance their growth and development.

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