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Children caring for their “caregivers”: exploring the caring arrangements in households affected by AIDS in Western Kenya

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Reflecting dominant understandings of childhood, many researchers describe orphans as an emotional and financial cost to the households in which they live. This has created a representation of orphans as a burden, not only to their fostering household, but also to society. This article seeks to challenge this representation by exploring children’s contributions to their fostering households. Drawing on research from Bondo District in Kenya, this article brings together the views of 36 guardians and 69 orphaned children between the ages of 11 and 17, who articulated their circumstances through photography and drawing. Nearly 300 photos and drawings were selected by the children and subsequently described in writing. An additional 44 in-depth interviews and three focus group discussions were conducted to explore findings further. The data suggest that many fostering households benefit tremendously from absorbing orphaned children. All orphans were found to contribute to their fostering household’s income and provide valuable care or support to ageing, ailing or young members of their households. The article concludes that caution should be exercised in using the term “caregiver” to describe foster parents due to the reciprocity, and indeed at times a reversal, of caring responsibilities.

Keywords: orphans; young carers; ageing caregivers; Africa; fosterage

Introduction

Maybe somebody is old and doesn’t have many relatives to care for him or her, but he or she is blessed with a grandchild – in such a case the grandchild will take care of the old grandparent.

Guardian in Western Kenya

As this statement suggests, children remain important for the care and support of less able family members in rural Kenya. Caregiving of adults by children is not a new phenomenon and may help to explain why 46% of older adults in sub-Saharan Africa are living with a grandchild (Zimmer & Dayton, 2005). Nevertheless, research into young caregiving in Africa is relatively recent (Bauman et al., 2006; Skovdal & Ogotu, 2009; Robson, 2000, 2004; Robson, Ansell, Huber, Gould, & van Blerk, 2006), linked to the more extensive body of research on young carers in the UK (Aldridge & Becker, 1993; Dearden & Becker, 2000) and Australia (Pakenham et al., 2007; Moore, 2007).

Whilst there are many similarities between young carers in UK and sub-Saharan Africa (Becker, 2007), understandings of childhood and the perceived competencies of children differ between contexts (Hutchby & Moran-Ellis, 1998). In this African context, children have historically spent large parts of their childhood away from their parents in an effort to spread both the costs and benefits of children (Caldwell & Caldwell, 1987; Lloyd & Desai, 1992). Nevertheless, the AIDS and orphan literature has predominantly looked at the human costs of fostering an orphan, downplaying the benefits and their contribution (Ennew, 2005). This is exemplified by studies looking at the anxiety (Ssengonzi, 2007), stress (Oburu & Palmerus, 2005) and financial hardship (Nyambedha, Wandibba, & Aagaard-Hansen, 2003b) faced by their guardians. Orphans have also frequently been described as “unsocialised”, “uneducated” and “unloved” (Barnett & Whiteside, 2006) “juvenile adults” (Kelly, 2003) who constitute an economic burden to their extended and fostering household (Guest, 2001).

Research of this nature has contributed to a simplistic view of parentless children as a burden to their fostering families, stretching the latter to the limit (Foster, 2000; Ssengonzi, 2009; UNICEF, 2003). This pessimistic view has gained a stronghold with researchers, the media and the aid industry, all of whom contribute to the representation of orphans as “helpless” and vulnerable and of their guardians as burdened (Ennew, 2005; Meintjes & Bray, 2005).

Alongside these pessimistic observations is a more nuanced and optimistic view which challenges the notion of AIDS causing societal breakdown (Abebe & Aase, 2007; Bray, 2003; Madhavan, 2004) and of
orphans being burdensome (Abebe, 2007; Ennew, 2005). The literature on young carers in Africa has also actively encouraged a move away from the focus on the “vulnerability” of children affected by AIDS to that of their resilience (Becker, 2007; Evans, 2005; Skovdal, Aoro, Ogutu, & Campbell, 2009).

This paper is a direct response to a call by Abebe and Aase (2007) for a more contextualised understanding of the “orphan burden” and of how such negative representations of orphans can impact on interventions in unhelpful ways. I am not disputing that households affected by AIDS need support, but argue for a more complex understanding of fostering arrangements in hope for more appropriate service delivery.

Methodology

This paper brings together two independent studies, both carried out in Bondo district, Kenya. Although the two studies had different aims and sampled orphans for different purposes, both studies revealed reciprocity of care within households.

Study area

Bondo is characterised by high levels of poverty and a HIV prevalence rate (13.7%) twice the national average (NACC, 2005). As a result, the issue of orphanhood is particularly relevant in Bondo with a third of children having lost one parent and one out of nine having lost both parents (Nyambetha, Wandibba, & Aagaard-Hansen, 2003a).

Study sampling

Study 1

Study 1 reports on the evaluation of a community-based capital cash transfer (CCCT) initiative in a small rural community (Tatu) made up of four villages in the Usigu division of Bondo District. The study took place in 2006 and aimed to explore the impact of the CCCT programme, which targeted orphans through their guardians. Study participants were randomly sampled from a list of beneficiaries. Children were given disposable cameras and encouraged to document their everyday life, after which they were invited to write down their thoughts on three of their favourite photos (see Figure 1). Ethical clearance was granted from the Centre for International Health and Development, University College London and the Department for Gender and Social Services in Kenya. The findings and details of this study have been documented elsewhere (Skovdal, Mwasiaji, Morrison, & Tomkins, 2008).

I want to talk about this photo because the land has helped me a lot. It has enabled us to get food to eat and to sell it to help us through diseases. When we are sent from school our mother can take some maize to the market, sell it and get money which can bring us back to school. Once our mother was sick and taken to hospital and the money from the sales of the produce was enough to pay the hospital.

This photo is telling us that we got money to pay for her treatment during the period in which she was in the hospital. The photo also tells the story about how we get money to pay for school. We are still in school.

The picture relates to my life because the farm made us the money to paid for school and now I am going to school and studying hard. The produce is also enough to sustain us, our cattle and other’s cattle graze on our land after harvesting.

Figure 1. Example of written narrative.

Study 2

Study 2 investigates the psycho-social well-being and coping strategies of children caring for ailing and ageing guardians in two rural communities (Moja and Mbii), located in the Usigu and Maranda divisions of Bondo District. Conducted in 2007, the children sampled for this study spent over 25 hours a week caring for their ailing or ageing guardians and were recruited by local community leaders. Again, photography was used to explore the views and perceptions of children. Due to the sensitivity of palliative AIDS care, children were trained on the ethical considerations of photography and encouraged to draw rather than photograph circumstances they deemed inappropriate to capture on camera, but still wanted to share. Ethical clearance was granted by the London School of Economics and Political Sciences Research Ethics Committee and the Department for Gender and Social Services in Kenya. Further details of this study are available elsewhere (Skovdal et al., 2009).
Data collection and analysis

Data were collected from 69 children (between 11 and 17) and 36 adults (see Table 1). Interviews and photography workshops were conducted in the local Dhluo language by three local youths trained in qualitative research techniques, one of whom was involved in both studies. The local investigators were involved in the translation and initial coding of the transcripts. Thematic network analysis (see Attride-Stirling, 2001) of the data from both studies led to 180 codes which were refined into basic themes. Ten of these basic themes are relevant to understanding the reciprocity of care and support evident within households affected by AIDS. These 10 themes have been rearranged into three organising themes (see Figure 2), making up a thematic network.

Table 1. Sample and methods summary.

<table>
<thead>
<tr>
<th></th>
<th>Study 1</th>
<th>Study 2</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>Participants</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>21</td>
<td>48</td>
<td>69</td>
</tr>
<tr>
<td>Adults</td>
<td>26</td>
<td>10</td>
<td>36</td>
</tr>
<tr>
<td>Written narrativesa</td>
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<td></td>
</tr>
<tr>
<td>Children</td>
<td>27</td>
<td>270</td>
<td>297</td>
</tr>
<tr>
<td>Individual interviews</td>
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<td></td>
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<tr>
<td>Adults</td>
<td>8</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>Children</td>
<td>3</td>
<td>24</td>
<td>27</td>
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<tr>
<td>Group interviews (n = 6)</td>
<td></td>
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<tr>
<td>Adults</td>
<td>3</td>
<td>–</td>
<td>3</td>
</tr>
<tr>
<td>Children</td>
<td>3</td>
<td>–</td>
<td>3</td>
</tr>
</tbody>
</table>

*aBased on their own photos and drawings.

Findings

Care giving: expectations and cultural norms

Cultural norms and expectations have an impact on care and fostering arrangements. One of these expectations relate to the duties of children and their perceived ability to help out in the household. One guardian, when asked what one can expect of a 10-year-old child replied:

That is pretty much a grown up. At that age she can do anything, she can wash T-shirts, she can wash your skirt, she can wash dirty clothes, that is a grown up. She can also fetch water, cook, mop the house and plaster it using cow dung. That’s a woman. (Female guardian in an interview)

In aligning children’s roles with those of grown ups, the guardian outlines the competence which adults in this setting often ascribe to children. Whilst children down to the age of 10 were often expected to find and prepare food, this contradicted how guardians themselves perceived their role, acknowledging it as an adult duty to provide for children. There was more of an agreement on the role of guardians in disciplining...
and socialising children – and it was through this understanding that many children contributed to the household.

*Interviewer: What responsibilities do adults have in bringing up a child?*

01: We should care for a child, cook for them food, treat them while sick, and provide them with essentials such as clothing, education. We should also preserve their rights.

02: A child’s needs are entirely the responsibility of the parents/guardian.

03: We have to provide them with knowledge and teach them to be good people.

04: If I have a 15-year-old child, I would expect such a child to differentiate between what is good and what is bad. I can help him/her to behave like an adult. S/he should know that if there are no vegetables in the house, s/he should fetch vegetables, fetch firewood, fetch water and cook. You should try and stop them from playing all the time. You have to give him/her rules. (Group interview with guardians)

These care and household support activities were seen as important for the socialisation of children. Children who provide care and support for an ailing or ageing individual were therefore often positively recognised by the community. Samuel, a 13-year-old boy who has been caring for his father and currently cares for a disabled friend and his sick mother says: “All that I have done makes me happy. This is because I don’t do bad things in the community, and the villagers love me seriously for that and the fact that I like helping sick people”. It is a combination of Samuel’s socialisation and local expectations and his caregiving circumstances that have allowed him to develop a positive caring identity. However, not all the children were able to ascribe positive meanings to their circumstances. Negative meanings were related to the disruptive impact caregiving had on their school performance and attendance as exemplified by 15-year-old Paddy:

I took this picture to show how I have been helping my mother since she has an unpredictable disease. It may come anytime and at those times I do not go to school. When she gets sick, I am forced to leave school to help her out. I clean the house, cook for her, feed her, wash her feet and look after the animals. It affects my education and makes me suffer. (Paddy, age 15, written narrative)

Paddy’s disruption to school attendance was dependent on the relapses experienced by his chronically ill mother, leaving Paddy with frequent but short periods out of school. Some children stayed in school, but performed poorly due to high absence rates and inability to concentrate in school.

In this context it was common to send children, for various lengths of time, to assist elderly relatives. This was particularly the case of daughters’ children, as daughters are still seen to have a greater caregiving responsibility than sons.

Children can help in various ways, they can assist the grandmother with her needs, like washing her clothes. If I see my mother is in need of help, I send my child and instruct her to help with whatever she needs. (Female guardian in a group discussion)

Local understandings of childhood as a period of duty and service means that children are seen as a valuable resource, particular in the care and support of sick and elderly adults – motivating sick adults to offer guardianship to orphaned children.

**Children caring for their “caregivers”**

The duties and responsibilities children take on are many and often necessary for the well-being of their guardians. Duties not only involve day-to-day cleaning and household upkeep, but also personal care and nursing.

I help my guardian by washing her, massaging her body with a cloth dipped in hot water and cleaning her feet. (Josephine, age 16, written narrative)
To sustain themselves and their guardians, many orphans engage in income generating activities. Boys in particular were found to engage in the burning of charcoal. Both girls and boys participated in farming activities as a way to get food and earn money for school equipment and other foods. Charles, for example, collects wood which is then burnt to make charcoal in order to support himself and his ageing guardian, for whom he is fully responsible.

We are burning charcoal so that we can get food. We are forced to do this because nobody is giving us food, we have to search for it ourselves and on top of this we have to look after our caregivers because they are too old to look after themselves. (Charles, age 16, written narrative)

Orphaned children engage in a variety of caregiving activities and assume different responsibilities. Some children provide significant productive and reproductive support to their fostering households, others engage in nursing care. The next section explores some of the psycho-social factors that encourage young caregiving.

Mutual empathy, love and respect

Although caring responsibilities and the time spent on caring for elderly “caregivers” differ between the households, many children like Charles and Syprose, assume full responsibility for their guardians.

Although many orphans realise that the responsibility of care should not solely be with them, many of the children take great pride in their caring duties. Twelve-year-old Mercy from Mbili says: “I think/feel that it is good to help old and sick people and it needs heart and love”. This love derives from deep respect and empathy for their guardians, even when the care they provide is not reciprocated beyond having shelter and a place where they belong. When
12-year-old Beryl was asked to describe the life of orphans she said:

They are suffering because one can be living with a grandmother who does not even care whether the orphan has clothes or not. What we should do in this case, we should assist them. They will appreciate and be grateful for that. (Beryl, age 12, interview)

Beryl’s advice to support and respect her non-supportive guardian may well be seen as strategic, in the hope and belief that her care and support will eventually be reciprocated. Orphans greatly appreciate the shelter and fostering they receive. One boy emphasised how he appreciated his guardian despite her difficult personality. When asked about difficulties living with his guardian, he said:

You know [here Nick smiles] even if there are difficulties, I can’t complain because she takes care of me. If she wasn’t there, I could be a street boy or a thief, so I don’t want to say anything bad about her, even if she is stubborn. (Nick, age 13, interview)

As a result of their gratitude for the guardians who give them shelter, the orphans aim to please their guardians and avoid disappointing them, resulting in them doing a lot of work.

I took this photo because it shows my guardian. I always help her out and she always gives me food at the right time and place. My guardian is very clever and honest; I give her respect and live up to my responsibility all the time. (Loyce, age 14, written narrative)

This respect is not only rooted in the rigidly hierarchical, even oppressive, social relations between children and adults that characterise Western Kenya. It also derives from the empathy they feel with vulnerable ageing or ailing guardians, and their desire not to be an added burden:

When we are in school our grandmother is working in the garden. After school we will help her, I join her in the garden and after which we shall go and fetch water in the nearest dam. The grandmother is suffering because of us and therefore we must also work hard to please her. (Jasmine, age 14, written narrative)

The data presented so far suggests that some orphans provide significant care and support to members of their household and do so for a number of different reasons. Figure 3 summarises some of the inter-linked factors that encourage orphans to provide care and support.

![Figure 3. Factors impacting on orphans providing care and support to their guardians.](image)

**Discussion**

Orphans are not necessarily the “helpless”, costly and passive beings they are popularly represented to be. In the absence of extensive old-age pension schemes and social security, orphans in Bondo contribute significantly to the welfare of the elderly and the sick.
They do so for a number of reasons, ranging from cultural expectations, sheer need and mutual love and respect. Some children cared for an ailing parent, others were sent by a parent to provide support to an ageing grandparent, and others, following the death of both parents, were absorbed by their extended family or community members. Whilst there appeared to be little difference between children living with an ageing or ailing guardian, children living with a sick guardian had more nursing duties.

In most cases, the children were grateful to be under their “care”. This was particularly the case of orphans who had nowhere else to go, and this gratitude was reflected in the respect, empathy and hard work that characterised their relationship with their guardian. The type of work done by the children differed. Most children merely helped out with the daily chores, yet some children were directly involved with the nursing of their guardian, and some assumed full responsibility for sustaining the household – thus playing a central, and often exclusive, role in the economic support of themselves and their guardians.

Whilst this paper has focused on the children’s competencies and their active role and ability to cope, one emerging hypothesis that requires further investigation is the possibility that ageing or ailing foster parents take advantage of the children’s orphan status and offer them a home in return for their care and support in sustaining the household. Despite these mutual benefits, such arrangements can compromise the school attendance and performance of these children – a problem which deserves our attention.

There is also a need for much greater care in the language used by policy-makers, development agencies and researchers in discussing these children and framing their support needs. Treichler (1988, p. 232) argues that “we must examine how language itself produces what we think we know; if we are to intervene, language is one place where that intervention must take place”. In order to challenge dominant representations of orphans as passive victims and burdensome, this article has highlighted the reciprocity, and sometimes reversal, of care and support responsibilities in the orphan-caregiver relationship, suggesting that “caregiver” may not always best represent the role of a foster parent, due to its simplistic representation of adults as the givers and children as the receivers of care. I suggest that “guardian” serves as a more neutral and appropriate term to describe the role of foster parents, and one which better reflects the reality of the reciprocity of care and support evident in fostering households.

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