



HAL
open science

Challenges faced by elderly guardians in sustaining the adherence to antiretroviral therapy in HIV-infected children in Zimbabwe

Morten Skovdal, Catherine Campbell, Claudius Madanhire, C Nyamukapa, Simon Gregson

► To cite this version:

Morten Skovdal, Catherine Campbell, Claudius Madanhire, C Nyamukapa, Simon Gregson. Challenges faced by elderly guardians in sustaining the adherence to antiretroviral therapy in HIV-infected children in Zimbabwe. *AIDS Care*, 2011, pp.1. 10.1080/09540121.2010.542298 . hal-00677867

HAL Id: hal-00677867

<https://hal.science/hal-00677867>

Submitted on 10 Mar 2012

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Challenges faced by elderly guardians in sustaining the adherence to antiretroviral therapy in HIV-infected children in Zimbabwe

Journal:	<i>AIDS Care - Psychology, Health & Medicine - Vulnerable Children and Youth Studies</i>
Manuscript ID:	AC-2010-04-0209.R1
Journal Selection:	AIDS Care
Keywords:	Pediatric AIDS, Anti-retroviral therapy, Adherence, Elderly guardians, Zimbabwe

SCHOLARONE™
Manuscripts

Challenges faced by elderly guardians in sustaining the adherence to antiretroviral therapy in HIV-infected children in Zimbabwe

Abstract

Grandparents throughout sub-Saharan Africa have shown immense courage and fortitude in providing care and support for AIDS-affected children. However, growing old comes with a number of challenges which can compromise the care and support given to children affected by AIDS, particularly for children infected by HIV and enrolled on anti-retroviral therapy (ART) programmes. For ART to have an impact, and for children not to develop drug-resistance, a rigid treatment regimen must be followed. Drawing on the perspectives of 25 nurses and 8 grandparents of HIV-infected children in Manicaland, eastern Zimbabwe, we explore some of the challenges faced by grandparents in sustaining ART adherence in HIV-infected children under their care. These challenges, serving as barriers to pediatric ART, are poverty, immobility, deteriorating memory and poor comprehension of complex treatments. Although older HIV-infected children were found to play an active role in sustaining the adherence to their treatment by contributing to income and food generating activities and reminding their guardians about check-ups and drug administration, such support was not available from younger children. There is therefore an urgent need to develop ART services that both support elderly guardians in their efforts to sustain the adherence of HIV-infected children under their care and to actively draw on the agency of older children in facilitating ART adherence.

Key words: Pediatric AIDS, Anti-retroviral therapy, Adherence, Elderly guardians, Zimbabwe

Introduction

The last couple of years has seen unprecedented progress in the availability of antiretroviral therapy (ART) in sub-Saharan Africa (WHO *et al.*, 2009), not least in Zimbabwe where both primary care and hospital-based HIV services are reaching some of the most isolated communities. As a result 215,000 (57% of those living with AIDS) people are estimated to access ART in Zimbabwe, with more people enrolling every day (UNAIDS, 2010). A survey carried out in 2008 estimates that 13% of all patients receiving HIV care from the health services in Zimbabwe are between 0-19 years of age, of which 33% are aged 0-4, 25%, 5-9 years; 25%, 10-14 years; and 17%, 15-19 years (Ferrand *et al.*, 2010). As the fight against HIV and AIDS continues, it is imperative that anti-retroviral drugs (ARVs) are accessible and that virologic suppression remains high. Virologic efficacy, or 'good adherence', is better achieved if patients stick to their ART regimen for 95% of the time (Attaran, 2007). Good adherence minimises resistance to affordable first line drugs (Barth *et al.*, 2011; Tanuri *et al.*, 2002) but has been identified as a challenge for

HIV-infected children and adolescents on ART (Arrive *et al.*, 2005; Bikaako-Kajura *et al.*, 2006; Fassinou *et al.*, 2004; Ferrand *et al.*, 2010; Polisset *et al.*, 2009; Weigel *et al.*, 2009). The Zimbabwean survey carried out by Ferrand and colleagues (2010) asked clinic staff from all ART distribution centres in the country about common problems faced by children and adolescents in accessing and adhering to HIV care regimens and they found that for young children (0-5), malnutrition, lack of appropriate drugs, erratic drug taking and hospital visits, orphanhood and caregiver issues (e.g. elderly, ill or unsupportive caregivers) were major issues. For adolescents (10-19), erratic drug taking was also a major obstacle to adherence, as was lack of disclosure and poor use of counselling and psychosocial services (*ibid.*). In our interest to develop an understanding of these obstacles to ART adherence, as well as to investigate the interconnections between obstacles to ART adherence and the age of children's caregivers, our focus will be on children who have outlived their parents and live with elderly guardians who also act as their treatment partner.

Although elderly people have been found to play a crucial role in providing care and support for adults infected with HIV (Knodel *et al.*, 2007), this is the first study to explore the caring role of elderly guardians in sustaining the ART adherence of children. Whilst many studies have already explored the care and living arrangements of orphaned children and their elderly guardians, these studies have a tendency to highlight how elderly guardians selflessly take on the burden of caring for orphaned and AIDS-affected children – often at the expense of their own health and well-being. Elderly guardians for example are reported to struggle with financial difficulties (Nyambedha *et al.*, 2003) and suffer from psychosocial distress (Boon, James *et al.*, 2010; Boon, Ruiters *et al.*, 2010; Oburu *et al.*, 2003, 2005; Ssengonzi, 2007). Whilst this may certainly also be the case of the elderly guardians reported on in this study, we believe there is a need to be realistic about the capabilities of elderly guardians, particularly in relation to their role in sustaining the ART adherence of HIV-infected children under their care – often under very difficult conditions. Furthermore, we also believe that such studies only give one side of the story. In line with dominant ideological understandings of children as passive beings in need of adult support and guidance (cf. Hutchby *et al.*, 1998; James *et al.*, 1998), they generally begin with the view of children as the problem ('the burden') and adults as the solution ('the burdened'). We seek to move beyond this conception, building on studies that have highlighted the reciprocity of care and support within such households (Abebe *et al.*, 2010; Skovdal, 2010). Although elderly guardians do – very importantly – provide orphaned and HIV-infected children with a home and place of belonging, their old age, illness and fragility may limit their contribution towards income and food generation, meaning they depend on the contribution and active participation of children in sustaining their livelihoods (Skovdal, 2010) and in some cases health (Skovdal *et al.*, 2009).

In this paper we extend this line of thinking by examining the challenges faced by elderly guardians – and the participation of children themselves – in sustaining the ART adherence of HIV-infected children under their foster care. This is an area of concern only previously mentioned in passing (e.g. Ferrand *et al.*, 2010; Meyers *et al.*, 2007; Raiman *et al.*, 2008). In South Africa for example, both Meyers, Moultrie *et al.* (2007) and Raiman, Michaels *et al.* (2008) report that elderly guardians have practical difficulties in administering ARV medication due to their often compromised visual and arithmetic skills. It is against this background, and in our interest to support elderly guardians in their efforts to sustain ART adherence in children, that we seek to explore the question: What challenges do elderly guardians face in contexts of poverty, AIDS and limited social services as they act as the treatment partners of children on ART? In exploring this question we hope gain knowledge that can help us develop programmes that better support the efforts of elderly guardians to provide the best possible treatment support for children under their care.

Methodology

This research forms part of an on-going study which was granted ethical approval from the Medical Research Council of Zimbabwe (A/681) and Imperial College London (ICREC_9_3_13). Informed and written consent was gathered from all research participants with the agreement that their identities would not be revealed. Pseudonyms have therefore been used throughout.

Study population and sampling

The study was conducted in three rural communities in Manicaland province of eastern Zimbabwe. The province is characterised by high levels of poverty and HIV. The three rural communities involved in this study are all served by rural hospitals or health clinics that distribute ART. This paper draws on the perspectives of 25 nurses and 8 elderly guardians of children enrolled onto an ART programme. Although 30 guardians of children with HIV participated in the larger study, these 8 guardians (the only guardians over the age of 50 participating in our study) all referred to their old age as a major physical and economic constraint to children's ART adherence and therefore qualify for inclusion in this paper. All guardians of HIV infected children were recruited through a mix of purposeful, snowball (using village community health workers) and opportunistic (self-selected informants) sampling, and in so doing actively sought to identify and recruit some elderly guardians. The age of the elderly guardians (all female) ranged from 52 to 79, with a mean age of 61.

The 25 nurses participating in this study were recruited from three health clinics on the basis of their willingness to participate. The nurses had a variety of experiences and came with different backgrounds, right from primary care and outreach programmes to HIV testing, ART distribution and palliative care. The nurses tend to live within the compounds of the hospital and have received training on the administration of pediatric ART. The mean age of the 25 nurses (11 female, 14 male) participating in the study was 40.

Data collection and analysis

The data for this study were collected in October and November 2009. Four experienced fieldworkers conducted 26 in-depth interviews (18 with nurses and 8 with elderly guardians) and one focus group discussion with 7 nurses in the local Shona language. The semi-structured topic guides used for the elderly guardians covered informants' personal background, their experiences of AIDS, stigma and being a treatment partners as well as problems and facilitators of children's ART access and adherence. Individual and group nurse interviews used the same topic guide. The topic guide asked the nurses about their experiences in providing HIV treatment for children, including barriers and facilitators, as well as their interaction with treatment partners. With permission, the interviews were digitally recorded, transcribed and translated into English by the fieldworkers. To ensure the accuracy of transcription and translation, 20% of all transcripts were randomly selected to undergo a quality check, including back-translation. No inaccuracies were identified. Individual and group interview transcripts of both nurses and elderly guardians were imported into the qualitative software package Atlas.Ti for thematic content analysis (Flick, 2002). Data collected by the two study methods and populations were pooled and analysed collectively to provide a holistic and comprehensive understanding of patterns (core themes) within the data corpus (Braun *et al.*, 2006). Using a social constructionist perspective, we sought to map out features of the collectively constructed representational field which shaped both nurses' and carers' understandings and actions, rather than seeking to document attitudes conceived of as properties of individuals (Gaskell, 2001). Following the steps of Attride-Stirling's (2001) thematic network analysis, text segments were first coded with an interpretative title, which were clustered into higher order, or primary themes. The outcome of this thematic network analysis is presented in Figure 1 which highlights the three primary themes that address the research question of this paper and make up the structure of our presentation of findings.

Figure 1: Thematic Network: Challenges (lessened by children's agency, see dotted boxes) faced by elderly guardians in sustaining the ART adherence of HIV-infected children

Findings

To contextualise our findings within the lived realities of the elderly guardians acting as treatment partners, Table 1 gives detail to the household composition of each of the eight guardians participating in this study. What Table 1 encapsulates is the impact of AIDS on families and the fostering role of older people. Several guardians had lost their husbands and children and were now the foster parents of their grandchildren, young nieces or nephews. As such, the table also highlights that elderly people were not necessarily alone in creating a supportive context for children on ART; there were often other children in the household who could help out. The HIV positive children on ART in the eight households described in

Table 1 were all on first line treatment (combination of Stavudine, Lamivudine and Nevirapine) which was administered on a weight-based system in tablets. Although syrups, which are more easily administered to younger children, are available, these are hard to access in Zimbabwe.

Table 1: Household characteristics of elderly guardians providing HIV care for children

Overall, great progress has been made in achieving children's access and adherence to ART in this context, however as we will now illustrate, HIV-infected children who live with their elderly guardians may face some barriers to optimal ARV adherence that are unique to their care arrangements.

Poverty and struggles

Households made up of elderly guardians and orphaned or AIDS-affected children are particularly vulnerable to poverty and related struggles. Such struggles are faced by Joanna who is too old to work and has difficulties paying for the schooling and clothing of her foster children.

“The problems I am facing are monetary including schooling and clothing. All these are solely my responsibility at the same time I am too old to work and this has been a major problem.”

Joanna (52), elderly guardian

Such struggles often result in children having to carry the responsibility of contributing to household sustenance, and on occasion HIV-infected and ill children are forced to engage in work. As one nurse commented:

“There are those who want to take advantage of these children. Maybe the child will be the only grandchild but he sends him to the grinding mill, to fetch water, to water the garden some being used that you feel pity. There was a case of a sick child, the grandmother was saying a-aah she works she even goes to fetch firewood. That child died”. Peter (35), nurse

In response to the poverty and struggles faced by ARV users in this context, a number of non-governmental organisations were reported to provide them with food aid, minimising pressures on sick children to engage in income and food generating work as well as providing them with a nutritious diet to support their treatment.

“Some of these children are being cared for by elderly guardians so they lack food but now that problem has been met because a lot of organizations are distributing food in the area.”

Jackie (36), nurse

Immobility

We have already alluded to the fact that some elderly guardians are unable to generate food and income. But in what other ways can their immobility compromise children's adherence to ART? ARV users in this context need to go for check-ups and pick up their drugs at a designated health facility on a monthly basis. Each visit costs US\$1, covering the administrative costs of the check-up, which, coupled with potential transport costs, can be a challenge for elderly people to pay. But the immobility of some elderly guardians can also prevent them from accompanying their children to their monthly review dates. This is particularly the case with young children who need to be carried.

“Like me at my age, to think of going there on foot or even to carry the child on my back, it's impossible and for me to get someone to help me take the child to hospital can be impossible. I can't even think of carrying a child on my back at my age, if I fail to get anyone who is kind enough to help me then there is little I can do.” Cellestine (54), elderly guardian

Other times the sheer distance can present as a barrier for guardians who had difficulties walking . They were also more likely to get sick and be periodically immobile, preventing the child from attending its review date and pick up ARV supplies.

“The health of some of the children who stay with their elderly guardians is not good and sometimes elderly people are not strong enough to come with the children to the clinic the distance might be near but the elderly guardian can't walk the child will end up defaulting.” James (36), nurse

“Elderly women, they would be coming from far away. For her to send the child by herself is not possible, for her to send someone with the child is difficult because of the issue of stigma, so they will remain at home and miss the appointment. If there was a mobile facility that would have helped”. Roselyn (57), nurse

However, carers repeatedly stated the strength of their commitment to ensure that children attended their monthly hospital review on the appropriate date.

“The only thing that can stop me would be if I fall ill myself, and I fail to find anyone to escort my child to the hospital, As for my chores at home, I will always leave them behind and take the child to hospital first”. Nokutenda (79), elderly guardian

Poor memory and comprehension

For some elderly guardians, remembering the review dates was a bigger challenge than immobility. Several informants spoke of difficulties faced by elderly guardians in remembering drug review dates, often only returning to the hospital when drugs had run out, resulting in a delay in the child's treatment.

"Sometimes these children will be staying with their grandmothers and these grandmothers are old, so they may sometimes forget the review dates, when they are and how many weeks they should wait before going back, so they end up forgetting everything, hence they delay to go and get the children's pills." Marjorie (53), elderly guardian

Forgetfulness can also mean that children are not reminded to take their drugs at a regular interval, with elderly guardians forgetting when the last drug was taken. This, coupled with a relative complicated administration of drugs may compromise the child's treatment.

"Some of them stay with grandparents who are too old, and who confuse the time or the drugs the child has to take." Evelyn (29), nurse

However it may happen that other household members, and children in particular, play an active role in helping their elderly guardians remember when drugs need to be taken.

"The other children are the ones who are reminding me, they remind him to take the tablets and they also tell me that he has taken the tablets and is now leaving for school." Nokutenda (79), elderly guardian

"No I do not forget to give the child the drugs. Even if I was to forget this kid himself would remind me. You hear him saying: 'Granny its six o'clock, time for my medication'." Violet (67), elderly guardian

A number of nurses spoke of problems in communicating with elderly guardians. They said the guardians often failed to understand the complexity of the child's treatment regimen. Nurses go to great lengths to ensure that treatment partners – people (often household members) who play a primary role in facilitating the treatment regimen of ARV users – have the tools and knowledge to facilitate child adherence, but these are often inadequate for elderly people who are unable to read and write. This is particularly a problem if the child in their care is still young and cannot assist keeping notes in their treatment schedule.

“Most of the children we have who are on ART are cared for by people who are very old. We give people adherence calendars that they should fill in, but what if she can't write, if she is 80 something years? The child may be around 4 or 6 years, so for her to write down and to properly administer the drugs may be challenging. She doesn't even know the name of the drug she is giving the child. You would have told her the name but she won't remember it, she just knows that the child is on medication, that's very tricky. Some of them they do not have middle aged people close to them to help them with taking care of the child, so its really a challenge.” Collin (27), nurse

As Miriam, a nurse, explains, many of the elderly guardians are aware of their limitations and actively remind the child to be alert to the advice they receive from the nurses.

“It's a challenge when you have to explain to an elderly person, especially the issue of food, I would be emphasizing what the child needs to eat, I will explain it to the child and I will do it thoroughly so that the child will remind the grandmother. The grandmother will actually call the child to be alert to what we will be saying, you realize that the child is now taking responsibility for all this yet it should be the other way round. When it comes to food, you will hear that the child has eaten only once, yet s/he should be eating more often than this for the drugs, so it's a challenge, there is a problem with elderly caregivers”. Judith (34), nurse

Discussion

The findings presented in this paper first and foremost highlight the commitment and dedication elderly people show in ensuring that children under their care comply with the rigid treatment regimens associated with ART, an asset previously identified in Cambodia (Williams *et al.*, 2008) and Thailand (Knodel *et al.*, 2009). In this paper we have illustrated that deteriorating mobility, memory and comprehension of complicated treatment plans, coupled with poverty in a context of limited social welfare and government support, make it difficult for some elderly guardians to sustain the treatment of HIV-infected children in their care – presenting a key adherence challenge for pediatric ART. Our findings suggest that support for elderly carers should address both their poverty- and age-related needs. Although these needs are interrelated, they require different interventions. Age-related challenges refer to their physical limitations (deteriorating memory, comprehension and mobility) and poverty-related challenges refer to their lack of income and food, encouraging the infected child to engage in income generating activities beyond what is good for them. Whilst the obstacles faced by elderly guardians took precedence in this paper, our informants did also highlight potential strategies that can help elderly people in their role as treatment partners

of HIV infected children. These included the distribution of food aid, encouraging children's agency and participation in the treatment, stigma-reduction programmes, increasing social support networks, mobile health facilities and improving the physical access to health facilities (e.g. constructing satellite clinics to reduce the distance).

It is clear that elderly people are ideally positioned as treatment partners to HIV-infected children by virtue of their living arrangements and associated emotional attachments (Knodel *et al.*, 2009). However, as some of the age-related challenges identified in this paper highlight, such arrangements could benefit from externally facilitated support. HelpAge International (2008) recommend that elderly carers, especially women, must have access to legal advice, financial support and literacy programmes, so that they can access entitlements for themselves and those in their care. Failure to address the rights of elderly people will undermine their ability to care for others. One way to address poverty-related challenges is to make financial support, such as social pensions, available. Social pensions targeting poor and vulnerable elderly people have been identified as a feasible intervention alleviating the impact of HIV and AIDS (Kakwani *et al.*, 2007; Schatz *et al.*, 2007). In the form of monthly cash transfers to elderly people, these could enable already committed elderly guardians to use the funds on direct and indirect expenses related to the treatment of children under their care (such as drugs or hospital fees, transport and food). Child-support grants, as seen in South Africa (Case *et al.*, 2005) and Kenya (Bryant, 2009) also have the potential to alleviate some of the poverty-related challenges identified in this paper as barriers to the adherence of ART in children.

In addition to cash transfers, social networks can be strengthened through community mobilisation and community health workers (or hospital outreach staff) to monitor and address the challenges specific to households with elderly guardians (Skovdal *et al.*, 2008; Skovdal *et al.*, 2010). Such services could encompass providing elderly people with locally appropriate mobility aids and alarmed watches to ensure timely follow-ups and medication as well as making information about treatment regimens accessible to elderly people. One of our informants also highlighted the need for mobile health services, suggesting the need to decentralise ART dispensing to local clinics as well as making outreach staff mobile so that they can reach immobile elderly guardians out in the communities.

This study also highlighted that in contexts of limited support, the agentic capabilities of older children (over the age of 10 as defined by Ferrand *et al.*, 2010) play a key role in coping with some of the challenges identified in this paper. Older children help with income and food generating activities and remind guardians about review dates and the administration of drugs. Therefore, to ensure the adherence to ART in children under the care of elderly guardian, there is an urgent need for HIV services to embrace and involve *both* the children and their elderly guardians in HIV programme planning. Older children living

in the household, whether HIV positive themselves or the older siblings of a younger positive child, need to be acknowledged as contributing agents to ART adherence. Not only will such an acknowledgement of children's agency help us move beyond unhelpful understandings of children as a 'burden' to 'burdened' elderly people, it also highlights the importance of involving older children in the treatment process.

To conclude, we believe that much more needs to be done to advocate for policies and programmes that take heed of some of the challenges and resources identified in this paper and promote more family/household centred HIV services that take account of the elderlies' needs for support, and acknowledge and enhance the agency of older children as active and responsible contributors to ART adherence. However, as this is a new area of research, further investigation into the prevalence of elderly treatment partners and the obstacles they are facing (e.g. segregated by the children's age) as well as the experiences of elderly guardians in other settings is urgently needed.

References

- Abebe, T., & Skovdal, M. (2010). Livelihoods, care and the familial relations of AIDS-affected children in eastern Africa *AIDS Care, iFirst*
<http://dx.doi.org/10.1080/09540120903311474>
- Arrive, E., Anaky, M. F., Wemin, M. L., Diabata, B., Rouet, F., Salomon, R., et al. (2005). Assessment of adherence to Highly Active Antiretroviral Therapy in a Cohort of African HIV-infected Children in Abidjan, Cote d'Ivoire. *J Acquir Immune Defic Syndr*, 40(4), 498 - 500.
- Attaran, A. (2007). Adherence to HAART: Africans take medicines more faithfully than North Americans. *PLoS Med*, 4(e83).
- Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, 1(3), 385-405.
- Barth, R. E., Tempelman, H. A., Smelt, E., Wensing, A. M. J., Hoepelman, A. I., & Geelen, S. P. (2011). Long-Term Outcome of Children Receiving Antiretroviral Treatment in Rural South Africa: Substantial Virologic Failure on First-Line Treatment. *The Pediatric Infectious Disease Journal, Publish Ahead of Print*, 10.1097/INF.1090b1013e3181ed1092af1093.
- Bikaako-Kajura, W., Luyirika, E., Purcell, D. W., Downing, J., Kaharuza, F., Mermin, J., et al. (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS Behav*, 10, S85 - S93.
- Boon, H., James, S., Ruiter, R. A. C., van den Borne, B., Williams, E., & Reddy, P. (2010). Explaining perceived ability among older people to provide care as a result of HIV and AIDS in South Africa. *AIDS Care*.
- Boon, H., Ruiter, R. A. C., James, S., van den Borne, B., Williams, E., & Reddy, P. (2010). Correlates of Grief Among Older Adults Caring for Children and Grandchildren as a Consequence of HIV and AIDS in South Africa. *Journal of Aging and Health*, 22(1), 48-67.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Bryant, J. (2009). Kenya's cash transfer program: protecting the health and human rights of orphans and vulnerable children. *Health and Human Rights in Practice*, 11(2), 65-76.
- Case, A., Hosegood, V., & Lund, F. (2005). The reach and impact of Child Support Grants: evidence from KwaZulu-Natal. *Development Southern Africa*, 22(4), 467-481.
- Fassinou, P., Elenga, N., Rouet, F., Laguide, R., Kouakoussui, K. A., Timite, M., et al. (2004). Highly active antiretroviral therapies among HIV-1-infected children in Abidjan, Cote d'Ivoire. *AIDS*, 18, 1905 - 1913.
- Ferrand, R., Lowe, S., Whande, B., Munaiwa, L., Langhaug, L., Cowan, F., et al. (2010). Survey of children accessing HIV services in a high prevalence setting: time for adolescents to count? *Bulletin of the World Health Organization*, 88, 428-434 doi: 410.2471/BLT.2409.066126.
- Flick, U. (2002). *An introduction to qualitative research* (2nd ed ed.). London: SAGE.
- Gaskell, G. (2001). Attitudes, social representations and beyond. In K. Deaux & G. Philogene (Eds.), *Representations of the social*. Oxford: Blackwell.
- HelpAge. (2008). *Stronger Together - Supporting the vital role played by older people in the fight against the HIV and AIDS pandemic*. London: HelpAge International.
- Hutchby, I., & Moran-Ellis, J. (1998). *Children and social competence : arenas of action*. London ; Washington, D.C.: Falmer Press.
- James, A., Jenks, C., & Prout, A. (1998). *Theorising Childhood*. Cambridge: Polity Press.
- Kakwani, N., & Subbarao, K. (2007). Poverty among the elderly in Sub-Saharan Africa and the role of social pensions. *Journal of Development Studies*, 43(6), 987 - 1008.

- Knodel, J., Kespichayawattana, J., Saengtienchai, C., & Wiwathwanich, S. (2009). *Older-age Parents and the AIDS Epidemic in Thailand: Changing Impacts in the Era of Antiretroviral Therapy*: UNESCAP (url: http://www.unescap.org/ESID/psis/Ageing/publications/Older_age_parents_and_AIDS.pdf retrieved on 14 April 2010).
- Knodel, J., & Zimmer, Z. (2007). Older persons AIDS knowledge and willingness to provide care in an impoverished nation: Evidence from Cambodia. *Asia Pacific Population Journal*, 22, 11-28.
- Meyers, T., Moultrie, H., Naidoo, K., Cotton, M., Eley, B., & Sherman, G. (2007). Challenges to Pediatric HIV Care and Treatment in South Africa. *The Journal of Infectious Diseases*, 196(s3), S474-S481.
- Nyambedha, E., Wandibba, S., & Aagaard-Hansen, J. (2003). "Retirement lost" - the new role of the elderly as caretakers for orphans in Western Kenya. *Journal of Cross-Cultural Gerontology*, 18, 33-52.
- Oburu, P., & Palmerus, K. (2003). Parenting stress and self-reported discipline strategies of Kenyan caregiving grandmothers. *International Journal of Behavioural Development*, 27(6), 505-512.
- Oburu, P., & Palmerus, K. (2005). Stress related factors among primary and part-time caregiving grandmothers of Kenyan grandchildren. *International Journal of Aging and Human Development*, 60(4), 273-282.
- Polisset, J., Ametonou, F., Arrive, E., Aho, A., & Perez, F. (2009). Correlates of Adherence to Antiretroviral Therapy in HIV-infected Children in Lomé, Togo, West Africa. *AIDS and Behaviour*, 13, 23-32.
- Raiman, S., Michaels, D., Nuttall, J., & Eley, B. (2008). A 4-pronged approach to addressing antiretroviral adherence in children: a paediatric pharmacy perspective. *SA Pharmaceutical Journal*, 75(8), 18-21.
- Schatz, E., & Ogunmefun, C. (2007). Caring and Contributing: The Role of Older Women in Rural South African Multi-generational Households in the HIV/AIDS Era. *World Development*, 35(8), 1390-1403.
- Skovdal, M. (2010). Children Caring for their 'Caregivers': Exploring the caring arrangements in households affected by AIDS in Western Kenya *AIDS Care*, 22(1), 96-103
- Skovdal, M., Mwasiaji, W., Morrison, J., & Tomkins, A. (2008). Community-based capital cash transfer to support orphans in Western Kenya: A consumer perspective. *Vulnerable Children and Youth Studies*, 3(1), 1 - 15.
- Skovdal, M., Mwasiaji, W., Webale, A., & Tomkins, A. (2010). Building orphan competent communities: experiences from a community-based capital cash transfer initiative in Kenya *Health Policy and Planning*, doi: 10.1093/heapol/czq039.
- Skovdal, M., Ogutu, V., Aoro, C., & Campbell, C. (2009). Young Carers as Social Actors: Coping Strategies of Children Caring for Ailing or Ageing Guardians in Western Kenya *Social Science and Medicine*, 69(4), 587-595.
- Ssengonzi, R. (2007). The Plight of Older Persons as Caregivers to People Infected/Affected by HIV/AIDS: Evidence from Uganda. *Journal of Cross-Cultural Gerontology*, 22, 339-353.
- Tanuri, A., Caridea, E., Dantas, M. C., Morgado, M. G., Mello, D. L. C., Borges, S., et al. (2002). Prevalence of mutations related to HIV-1 antiretroviral resistance in Brazilian patients failing HAART. *Journal of Clinical Virology*, 25(1), 39-46.
- UNAIDS. (2010). *Zimbabwe - 2010 Country Progress Report* Geneva: UNAIDS http://data.unaids.org/pub/Report/2010/zimbabwe_2010_country_progress_report_en.pdf (retrieved on 9 April 2010).

- Weigel, R., Makwiza, I., Nyirenda, J., Chiunguzeni, D., Phiri, S., & Theobald, S. (2009). Supporting children to adhere to anti-retroviral therapy in urban Malawi: multi method insights. *BMC Pediatrics*, *9*(1), 45.
- WHO, UNAIDS, & UNICEF. (2009). *Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector - Progress Report* (September 2009 ed.). Geneva: WHO Press http://www.who.int/hiv/pub/tuapr_2009_en.pdf (retrieved 12/05/2010).
- Williams, N., Knodel, J., Kim, S., Puch, S., & Saengtienchai, C. (2008). Overlooked potential: older-age parents in the era of ART. *AIDS Care*, *20*(10), 1169-1176.

For Peer Review Only

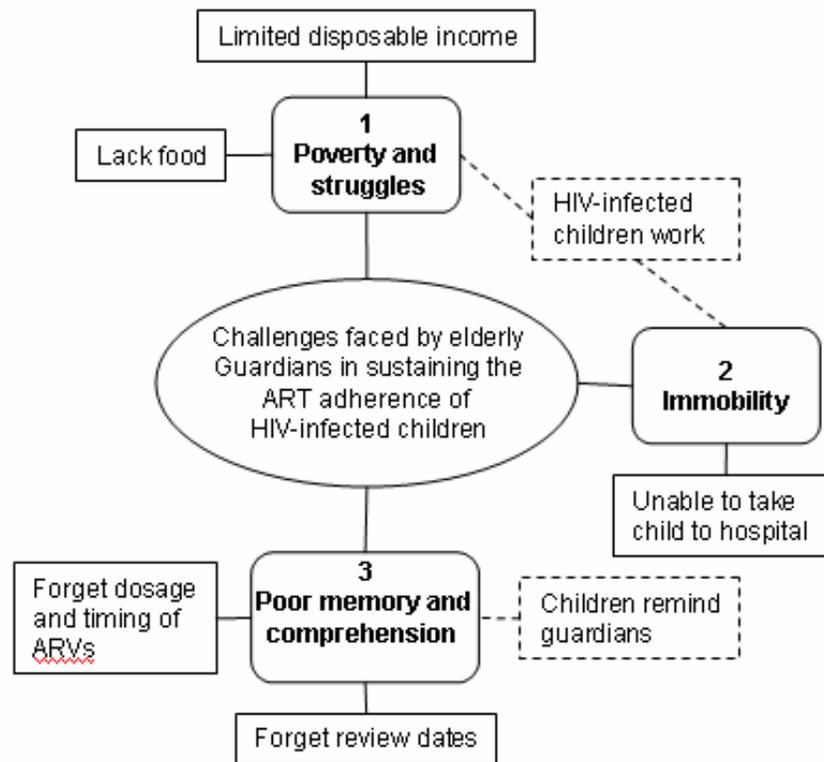


Figure 1: Thematic Network: Challenges (lessened by children's agency, see dotted boxes) faced by elderly guardians in sustaining the ART adherence of HIV-infected children

Table 1: Household characteristics of elderly guardians providing HIV care for children

Elderly guardian	Household characteristics
Nokutenda, age 79	Nokutenda stays with five grandchildren between the ages 4-12, of which one 8-year-old girl is HIV positive and on ART. Nokutenda's husband, two sons and two daughters have all died and she survives through subsistence farming.
Sandra, age 59	Sandra lives with her husband, mother-in-law, her sick daughter and her three grandchildren. One of her grandchildren, a 16-year-old girl, is HIV positive and on ART. She and her husband provide for the household through subsistence farming.
Carolyn, age 56	Carolyn stays with her brother and 6-year-old niece, both of who are HIV positive and on ART. The 6-year-old girl is separated from her older brother who is under the care of other family members. Carolyn's son occasionally visits and supports Carolyn financially.
Tanyaradzwa, age 70	Tanyaradzwa stays with her two great grandchildren, including a 4-year-old boy is HIV positive and on ART. Her grandson (children's father) has gone to the city to look for work. Their mother has died. Her 10-year-old great granddaughter helps Tanyaradzwa to care for the boy.
Violet, age 67	Violet stays with three grandsons, the oldest being 12, HIV positive and on ART. Her son (father of her grandchildren) and her daughter-in-law have both died. Violet sustains the household through subsistence farming.
Joanna, age 52	Joanna stays her ill son, her sister's 20-year-old daughter and her brother's three boys, of which a 9-year-old is HIV positive and on ART. Joanna works as a sales woman, buying and selling goods at the local market.
Cellestine, age 54	Cellestine and her husband live with their three grandchildren, of which the oldest, a 11-year-old girl is HIV positive and on ART. Cellestine and husband provide for the household through subsistence farming.
Marjorie, age 53	Marjorie stays with her 6-year-old grandson who is HIV positive and on ART. She stayed with her daughter and son-in-law until recently when they both died. Marjorie sustains herself and her grandson through subsistence farming.

Referee: 1

Comments to the Author

This study presents qualitative research done to identify the challenges faced by elderly caregivers supporting adherence to the anti-retroviral therapy (ART) for HIV infected children in Zimbabwe. In order to understand the scope of the problem and develop strategies to maintain adequate treatment of HIV infected children, this question is of importance. The results of this study are of particular relevance for the African countries where elderly guardians provide care for the HIV infected children living in poverty.

The following deficiencies must be addressed:

(1) "Introduction" has to expand the description of the previous publications in this field and their deficiencies, and the innovation in the approach and importance of the present study. Please, clarify the main goal and provide a solid "Introduction" (do not divide the introduction into parts). Combine "Introduction" and "Elderly caregivers in Africa". Avoid repetition by combining the sentences with the same information.

The introduction has been re-written and the two sections have been combined. Repeating sentences have been omitted and we believe the paper now has a more solid introduction with more literature and contextual information framing the contribution of this paper.

(2) "Methodology" must focus on the description of the study population, sampling, and questionnaire must also be presented. Please, clarify the definition of elderly people. Because all of them were grandparents of HIV infected children and age ranges varied widely, I suggest using "grandparents" to describe the study group.

We have provided an overview of the topic guide in the text.

We have expanded on the description of the study population and how they were sampled.

In the first draft of this paper we drew on the perspectives of all child carers (treatment partners of children on ART) participating in the on-going study. However, as the reviewers wanted more detail about the household compositions of elderly guardians and suggest we refer to them as grandparents, we found it impossible to incorporate all 30 child carers in the study. We have therefore decided to only include the perspectives of the 8 elderly guardians participating in the study. The sample size of the study has therefore changed from 25 nurses and 30 child carers to 25 nurses to 8 elderly guardians. We do not feel that grandparent is the appropriate term as two of the elderly guardians are the aunts of the children.

Although the authors presented the type of questions posed to identify the challenges for the grandparents, there is no information regarding the questions the nurses were asked.

We have now added: "The topic guide asked the nurses about their experiences in providing HIV treatment for children, including barriers and facilitators, as well as their interaction with treatment partners." We can't add more details because of the word limit.

Sentences starting with "HIV prevalence..... and Recent years....." should be used in "Introduction".

These sentences have now been moved to the introduction

(3) "Findings" should include description of the studied population (gender, age mean +/-SD, level of poverty, employment of the family members, number of children with AIDS in the family, availability of parents, age of infected children, biological relationship with children, type of therapy used).

A table has been produced outlining the details we have of each household. The type of therapy used has been described in the beginning of the findings section (e.g. "The HIV positive children on ART in the eight

households described in Table 1 are all on first line treatment (combination of Stavudine, Lamivudine and Nevirapine) which are administered on a weight-based system in tablets. Although syrups, which are more easily administered to younger children, are available, these are more difficult to access and are limited in Zimbabwe”.)

The results that were obtained from the two studied populations (grandparents and nurses) must be separated. They can not be combined because the populations are different, and therefore see the problem from different perspectives.

We are of the opinion that populations can be combined in order to identify common themes and patterns across data collection methods and populations. As both nurses and grandmothers spoke about the limitations of old age, we have combined their perspectives to report on more holistic themes that transcend the perspectives of individuals or small groups of people. We appreciate there are different opinions on how to analyse qualitative research and we have therefore constructed a clarifying sentence that outlines our social constructionist way of doing it:

“Data collected by the two study methods and populations were pooled and analysed collectively to provide a holistic and comprehensive understanding of patterns (core themes) within the data corpus (Braun *et al.*, 2006). Using a social constructionist perspective, we sought to map out features of the collectively constructed representational field which shaped both nurses’ and carers’ understandings and actions, rather than seeking to document attitudes conceived of as properties of individuals (Gaskell, 2001).”

Please describe the activities in the focus group. Such as, it is not clear how many did not participate in the discussion.

All 7 participants of the group discussion participated actively in the interview. We have clarified that only 7 nurses participated through a group discussion. There were no particular activities in the nurse group discussions, so we have further highlighted that a topic guide was used and what questions it covered:

“Four experienced fieldworkers conducted 26 in-depth interviews (18 with nurses and 8 with the grandmothers) and one focus group discussion with 7 nurses in the local Shona language. The semi-structured topic guides used for the grandmothers covered informants’ personal background, their experiences of AIDS, stigma and being a treatment partners as well as problems and facilitators of children’s ART access and adherence. Individual and group nurse interviews used the same topic guide. The topic guide asked the nurses about their experiences in providing HIV treatment for children, including barriers and facilitators, as well as their interaction with treatment partners.”

(4) “Implications for policy and practice” should be started with the conclusion, otherwise it is not clear what results can be used to change the policy and improve the practice. No study is needed to identify the financial, literacy, and health problems faced by the grandparents of HIV infected children in Zimbabwe. I think the discussion has to emphasize the main point - How to decrease the impact of the grandparent’s financial, literacy, and health problems on adherence to the medical treatment of the HIV infected children. Because eliminating poverty in a country is a long-term process, however, HIV infected children need adequate treatment today, and cannot wait for tomorrow.

It would be important to identify the participants’ opinion regarding their needs to maintain adherence to ART treatment of their grandchildren or foster children. No such question was discussed in the present study.

We think that strategies to maintain adherence were presented in the findings section, albeit we acknowledge that these were not flagged up adequately in the discussion. The quotes selected for the manuscript were carefully selected to illustrate both their needs and potential strategies. Whilst this was

not always possible to find such a quote, many of the quotes in this paper do point to what e.g. elderly treatment partners would suggest is a strategy to overcome their obstacle (although sometimes this would only be implicit) (e.g. the need for food aid, need for health facilities to be closer to them, mobile facilities, increased involvement of the children etc.). We acknowledge that we do not explicitly say what the recommendations were, but we have amended the discussion accordingly:

e.g.

“Whilst the obstacles faced by elderly treatment partners took precedence in this paper, our informants did also highlight potential strategies that can help elderly people in their role as treatment partners of HIV infected children. These included the distribution of food aid, the involvement of other children within the household, stigma-reduction programmes, increasing social support networks, mobile health facilities and improving the physical access to health facilities (e.g. constructing satellite clinics to reduce the distance).”

Overall main deficiencies of the present study: (i) participants were not selected randomly and this decries external validity of the present study;

We use a social constructionist conceptual framework – the extent to which the findings would be generalisable to other populations would have to be assessed by a skilled observer on a case by case basis (Flyvberg (2001) Making social science matter : why social inquiry fails and how it can count again), and we use the criterion of PUBLIC ACCOUNTABILITY (Bauer and Gaskell, Chapter 19) rather than validity and reliability. We don't have the word count to explain this at length, however we believe that most social scientists should be familiar with a social constructionist perspective, and that having identified it in our methodology section, no more detailed discussion is necessary

(ii) no separation of results between the two groups of participants (grandparents and nurses); (iii) no discussion regarding the participants (grandparents and nurses) vision regarding what would be really helpful for the families in poverty, low literacy, and poor health to provide adequate care of the HIV infected children.

The Table presented at the start of the findings section seeks to provide more contextual background.

Referee: 2

Comments to the Author

Article Summary:

This article details a qualitative study of challenges to maintaining antiretroviral adherence in African children in the care of elderly guardians. The identification of these challenges was based on interviews and focus groups conducted with caregivers and nurses in 3 communities in Zimbabwe. Elderly caregivers play an important role in caring for children with HIV in many African nations, particularly for orphaned children. However, the age and living conditions of these caregivers give rise to several specific difficulties with respect to maintaining adequate adherence to ARV medications. The primary challenges to adherence identified were poverty, immobility, poor memory and inadequate understanding of medication instructions on the part of caregivers.

This study collected interview and focus group responses from thirty caregivers and twenty-five nurses from three rural communities in Zimbabwe. Respondents ranged in age from 39 to 79 with a mean age of 54. This information was collected by four field researchers over the course of two months. Discussions were conducted in the local language and subsequently translated into English. Themes from the interviews were derived through software analysis. The authors suggest a need for increased social services, such as mobile clinics, social pensions, or child welfare grants in order to address the needs of this population. The authors also encourage further development of the positive resource of older children as assistants in the process of maintaining medication adherence.

This manuscript has the potential to contribute to the literature, however some important albeit minor concerns need to be addressed as follows:

Minor Concerns:

1. More specific demographic information would be helpful. Caregiver age range and mean age are provided, however, one is left to assume all caregivers are female. It would be helpful to include caregiver gender, caregiver health status (HIV+ vs other medical condition, if known), how many HIV+ children vs total children each caregiver is responsible for, and the age ranges of these children. Given the age range, mode of caregiver age might be more meaningful, or at the very least to indicate how many were over age 50.

At the start of the findings section we have included a table that depicts most of the household demographics the reviewer is looking for. Unfortunately, we do not have information about the caregiver health status.

It would also be helpful to know when referring to older children, what age is meant by "older". It would also be important to know how many from each community participated to know whether any one community was more open than the other(s). Similar nurse demographics would be informative.

We have included nurse age and gender demographics in the methodology. We have defined "older" as over the age of 10, which also reflects the findings of Ferrand as referenced in the introduction.

2. Given it is reported 30 guardians and 25 nurses participated, it would be helpful to know how many of each were interviewed individually versus participated in a focus group. How many focus groups were conducted in each community and how many participants were in each focus group? Given the mention of stigma, how difficult was focus group recruitment and how open was the discussion?

"Four experienced fieldworkers conducted 26 in-depth interviews (18 with nurses and 8 with the grandmothers) and one focus group discussion with 7 nurses in the local Shona language."

As the one focus group discussion involved in this study was with nurses who have been trained on AIDS and work with AIDS patients on a daily basis, stigma was not an issue for the group discussion.

3. Were the three communities included in the study analyzed for any differences between them? If so, were any differences noted?

No, the communities were not analysed for any difference. We included three communities to optimise variety in responses and to get increase the number of participants. The frame of reference of the paper is Manicaland province, all Shona and rural or semi-rural as specified in the methodology section. We do not feel that a fine grained analysis of differences between the communities would have yielded helpful findings in light of research question/objectives.

4. Similarly, were there any differences observed by recruitment method?

No, this was not the focus of the paper. The aim was to generate patterns of core themes across methods and participants.

5. There's always a question of accuracy given transcription and translation between languages. It is noted that interviews were conducted in the native language and translated into English. Was back-translation from English to the native language conducted to assure intended meaning of the communication was upheld in the translation?

Yes, due to word limits this was not previously included. We have now included a sentence in the methodology which reads: "To ensure the accuracy of translation, two interviews were randomly selected and back-translated. No inaccuracies were identified."

6. Figure 1 is not discussed in the text. While the figure poses challenges elderly caregivers face, HIV+ children working and children helping with medications appear to be solutions to the problems and should be depicted differently as real-life accommodations to the challenges faced. A second Figure could include these factors as accommodations that occur in reality with an overlay of proposed solutions to address the problems.

That's a really good point. We are now referring to Figure 1 in the manuscript text and have dotted the two boxes in figure 1 that mention facilitators to the challenges faced by elderly guardians. We felt this was the best way to distinguish between challenges and facilitators and keep 1 figure.

7. The authors discuss the potential positive effects of older children assisting in promoting adherence. It would be helpful to know how many reported assistance from children who are HIV+ versus siblings who are negative.

I am afraid we do not have any numbers to highlight this. However, to help the reader make his or her own judgement on this topic, we have tried to provide some more detail to the households in which grandparents are caring for children on ART. See newly added table for example.

8. NGO is not defined (page 5).

Apologies. As we only refer to NGOs once, we have spelled out the abbreviation.

9. Minor grammatical and typographical errors need to be addressed throughout.

We have had the manuscript proof read.