



"I am taking care of my granny properly and she is taking care of me."

Intergenerational issues between older caregivers and children in the context of AIDS in eastern and southern Africa

A collaboration between HelpAge International and the Regional Interagency Task Team on Children and AIDS - Eastern and Southern Africa

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Findings on older carers written by Douglas Lackey, HelpAge International

Findings on children written by Glynis Clacherty, Consultant

Literature review written by Patricia Martin, Consultant

Produced and edited by Lucy Hillier, RIATT-ESA

Additional copy editing and proofing by Christopher Bjornestad, Consultant

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Contents

i. List of Acronyms	1
1. Executive summary.....	2
2. Introduction.....	6
3. Research methodology	7
3.1 Definitions.....	7
3.2 Research methodology – Literature review	7
3.3 Research methodology - Older carers.....	8
3.4 Research methodology - Children living with carers	9
3.5 Data analysis	12
3.6 Limitations.....	13
4. Findings.....	14
4.1 Review of literature - Summary of findings	14
4.2 Findings – Research with older carers	17
Theme 1: The nature of the households.....	17
Theme 2: Perceived role of older carers in caring for children orphaned by AIDS.....	18
Theme 3: Difficulties older people face as care givers.....	18
Theme 4: Dealing with sexuality issues.....	21
Theme 5: How caregivers handle discipline.....	23
Theme 6: Abuse of children	25
Theme 7: Handling psychosocial care issues: Stigma, stress and depression among the children.....	26
Theme 8: Dealing with disclosure of parents’ death.....	27
Theme 9: Comparison with raising own children.....	29
Theme 10: Challenges faced by caregivers in providing care for children and ways of overcoming challenges	30
Theme 11: Lessons older caregivers learnt in caring for children	33
Theme 12: Recommendations from older carers for future support.....	34
4.3 Findings - Children living with older carers.....	36
Theme 1: How children describe their older-headed households	37
Theme 2: Children living in older-headed households have a heavy burden of work.....	41
Theme 3: The relationship between children and their older carers	44

Theme 4: Difficulties children living with older caregivers face	50
Theme 5: Children and grandparents see schooling as very important but poverty makes access and progress difficult	54
Theme 6: Emotional stress.....	56
Theme 7: Discussing sexuality	57
Theme 8: Talking about our parents	58
Theme 9: Grandchildren worry about their future	59
5. Comparison, synthesis and summary of findings from children, older carers and literature review.....	61
6. Recommendations	65
7. References.....	68

i. List of Acronyms

ACRWC	African Union Charter on the Rights and Welfare of the Child
AIDS	Acquired immune deficiency syndrome
AU	African Union
BEAM	Basic Education Assistance Model
CEDAW	Convention on the Elimination of Discrimination against Women
CRC	Convention on the Rights of the Child
CSC	Consortium for Street Children
CSO	Civil society organisation
FGD	Focus group discussion
HAI	Help Age International
HIV	Human immunodeficiency virus
HSRC	Human Sciences Research Council
JLICA	The Joint Learning Initiative on Children and HIV/AIDS
NGO	Non-governmental organisation
PEPFAR	President's Emergency Plan for AIDS Relief
REPSSI	Regional Psychosocial Support Initiative
RIATT-ESA	Regional Inter-Agency Task Team on Children and AIDS – Eastern and Southern Africa
SADC	South African Development Community
STI	Sexually transmitted infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session (on HIV and AIDS)
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WHO	World Health Organisation
VCT	Voluntary Counselling and Testing

1. Executive summary

This study responds to regional recommendations to strengthen families as a unit of care within the context of children affected by HIV and AIDS. In particular it addresses the recommendation to strengthen the skills of child, youth and older caregivers with age- and gender-sensitive training, including life and parenting skills, and awareness on sexuality and HIV and AIDS.

An operations research study was undertaken comprising a literature review and qualitative field research with older carers and children in seven countries in eastern and southern Africa. The objective of the research was to better understand intergenerational issues for older carers and children orphaned by AIDS and identify policy gaps, lessons learnt, and good practices with regards to support mechanisms for the enhancement of intergenerational relationships.

The findings of the research, which used a participatory approach with Focus Group Discussions (FGDs) and workshops as its central methodology for gathering data, for the most part supported the findings of the literature review. Interestingly, what came out of the research, which was absent in the literature, was the two-way nature of the caring, with children also taking care of their older carers.

The collective findings of the study highlighted:

- Households comprising older caregivers and the children for whom they care are confronted by a host of challenges; challenges which create a secondary crisis for these families. Older carers, mainly older women, lack regular income support, are food insecure and have been forced to sell their assets, including land, to meet the basic needs of children under their care.
- Time given to caring reduces older carers' ability to undertake income-generating activities. They struggle to provide parental support as well as ensure their grandchildren receive an education.
- Older carers find it difficult to maintain good health and the health of the children under their care. Significantly, older carers find it challenging to assume the role of a parent and impart the relevant and appropriate life skills and psychosocial support. They also need psychosocial support stemming from the grief felt as resulting from the loss of their adult children and the stress of providing adequate care for their grandchildren.
- Children living in households headed by older people often have more, and physically heavier, household duties than other children. They also often have the burden of earning incomes, and many of them care for their ageing grandparents in addition to this work.

- Children from these households struggle to stay in school, usually because household demands and because of a lack of money for school fees and other related costs.
- Finally, they carry a heavy burden of emotional stress derived from their grief for dead parents, combined with fear about their future.

Together, these factors impact significantly on the quality and dynamics of the relationship between older carers and the children they care for.

The following recommendations emanating from this study have been identified as important for the support and care of children and older carer households:

Older-headed households as a positive form of care for children

- The relationship between children and older people is largely reciprocal. It is important to remember that children provide a supportive and protective role for the older people in these households. Children who live with grandparents are happy, on the whole, with the relationships they have in the household. They prefer to live with grandparents than with other relatives or foster families. The findings of this research point to the fact that every effort should be made to support intergenerational households as a positive alternative form of care for children who are orphaned and for the older people themselves. This requires embracing a family-centred, integrated approach to the challenges and needs of children and older carers affected by AIDS.

Focus on the rights of older caregivers and the children in their households at national, regional and local level

- This research shows that the right of older caregivers and the children in their households to basic needs is violated. Human rights frameworks at the global, regional and national level need to build in indicators which directly address the rights of older-headed households. Rights-based indicators that relate to older-headed households should also be built into revised UNGASS indicators and the M&E frameworks for regional and national minimum package of services and psychosocial support for children.
- Regional and national policies, strategies and programmes across the sectors (HIV and AIDS, Children, Social development, Education and Agriculture) should be reviewed by policy makers in order to address the specific needs of older carers and children. Regional and national plans of action need to include programmes which provide relevant and appropriate support to older-headed households affected by the impact of HIV and AIDS.

- Lack of inheritance rights, or the lack of implementation of relevant legislation, place households headed by older people at risk. Review of legislation around inheritance and advocacy to implement it where it exists should be priorities. Paralegal advice and other legal services, including will writing, should be part of any programme working with older headed households.
- Children who come from older-headed households are discriminated against at school. Schools often require provisions beyond the capacity of the households. Advocacy at and within the school system needs to emphasise the need to adapt requirements for children who come from very poor households.
- Children and older people who live in older-headed households struggle to access health care. Finding money for medicines places an extra burden on them. Advocacy at policy level needs to focus on helping older-headed households' access health care more easily.
- Children living in older-headed households do work that violates many of their rights. Alongside supporting these households through social security (so that the children do not need to work) advocacy needs to focus on educating communities about the danger of inappropriate work for the growth and health development of children.

Programmatic support for older-headed households

- Civil society organisations (CSO) have a major role to play in supporting older carers and children. CSOs should review their strategies and programmes to reflect a family-centred and caregiver approach to reach older carers and children.
- Households headed by older carers have reduced agricultural capacity and cannot be self-sustaining because there is reduced labour. Programmes to support the agricultural capacity and livelihoods of older-headed households need to be implemented. These need to be tailored to the reality of families that have little physical capacity.
- Intergenerational relationships in older-headed households are negatively affected by the deep poverty that many of the households find themselves in. Social protection measures including social transfers need to be put in place to support households headed by older people - this will contribute not only to the physical wellbeing of children and the older people who care for them but also to their emotional wellbeing.
- Older carers face significant emotional stress because of their own grief and because of the responsibilities forced on them by the loss of their own children. This research points to the value older carers place on support groups for them where they exist. Psychosocial support targeted at older

carers needs to be put into place to help them cope with the demands of parenting and the responsibilities they face. Local support groups are an important way of doing this.

- Children living in older-headed households experience significant emotional stress. This is caused by grief over the loss of their parents which had not been dealt with, the poverty they experience and the extra work they have to do. They also worry about their future. Psychosocial support targeted specifically at the emotional needs of children living in these households needs to be provided.
- Older carers face challenges related to communicating with and raising children and teenagers, as well as challenges they did not face when they had to bring up their own children, such as helping to protect the children from HIV and AIDS. Older carers need education and support in parenting and communication skills.

Participation of older people and children

- This research shows that older carers and children have insights into their lives and circumstances that would enable more effective legislative and programme intervention. They should be involved in designing, implementing and monitoring programmes that concern them. Formal structures and systems should be created for meaningful older caregiver and child participation at national, district and community levels.

2. Introduction

Sub-Saharan Africa has been severely affected by the AIDS epidemic. UNAIDS and WHO (2009) report that in 2008 this region accounted for 67% of HIV infections worldwide, 68% of new infections among adults and 91% of new HIV infections among children. The predictions are that in the absence of significant behaviour change, these figures will increase.

No generation is spared the impact of the pandemic. The disease has seen high mortality rates amongst adults aged 15 – 49. This in turn has had a huge impact on the lives of the parents of the middle generation as well as those of their children. The number of AIDS-related deaths in 2001 was 1.4 million and there was no decline by 2008. This implies that there has not been a decline in the number of potential children orphaned by AIDS with a significant number being cared for by an older carer (UNAIDS AIDS Epidemic Update 2009).

UNAIDS and WHO estimated that there are 12 million children orphaned by AIDS in sub-Saharan Africa (UNAIDS 2008). It is estimated that between 40 per cent and 60 per cent of orphaned children in sub-Saharan Africa are cared for by their grandparents, particularly grandmothers (UNICEF 2007). Grandparents are therefore becoming ‘new’ parents at a time when they themselves need care and support in old age.

The Regional Inter-Agency Task Team on Children and HIV and AIDS - Eastern and Southern Africa (RIATT-ESA) is a multi-sectoral network of organisations working on care and support issues for children affected by AIDS in the region. In 2008 RIATT-ESA held a regional conference in Dar es Salaam, Tanzania, which identified a number of recommendations and priorities linked to older carers. Recommendations for action from the conference were grouped into four thematic areas which eventually led to RIATT-ESA forming thematic working groups in order to take forward certain recommendations.

The groups are:

- Keep parents and children alive;
- Strengthen families as a unit of care;
- Increase effectiveness of services and funding;
- Human rights for vulnerable children.

The “strengthening families as a unit of care” working group selected as its focus the recommendation: “*Strengthen skills of child, youth and older caregivers with age and gender sensitive training, including life-and parenting skills, and awareness on sexuality and HIV and AIDS*”. This addresses the intergenerational relationship challenges of older carers and children.

This report includes a summary of the literature review and the full report on findings from the focus group discussions with older carers and children.

3. Research methodology

3.1 Definitions

This research report uses the following definitions:

Older-carer – in the African context a woman or a man who is over 50 years old and is the sole caregiver of children under 18. Often the older carer is a grandfather or grandmother to the children but not always – great grandparents and older aunts and uncles are also carers.

Older-carer household – a household headed by a man or a woman who is over 50 years old where there are one or more children under 18 years. In most cases this is a skipped-generation household because the children’s parents (or older persons own children) have died or are absent from their care.

Skipped-generation household – as above for older-carer household

Children – children under 18 years old

Orphan – a child whose mother and father have died or are absent from their care. Note that we do not use the term Orphan and Vulnerable Child (OVC).

3.2 Research methodology – Literature review

Various sources of information were reviewed in order to identify and analyse the policy frameworks, strategies and action plans that record the commitments made by the global community to its orphaned children and older caregivers.

These sources include:

- international, continental and regional conventions emanating from the United Nations such as the Convention on the Rights of the Child (CRC), the Convention on the Elimination of Discrimination against Women (CEDAW); the African Union (AU), most notably the African Charter on the Rights and Welfare of the Children (ACRWC) and the AU Policy Framework and Plan of Action on Ageing, and the Southern African Development Community (SADC), particularly the OVCY strategic framework, minimum package of services and psychosocial support for OVCY;
- national policies and laws in nine African countries relevant to the provision of care and support for orphans and vulnerable children ;
- reports tracking progress against the various obligations imposed by international instruments, such as UNICEF’s State of the World’s Children reports;

- country-specific reports from respective ministries reporting on domestic compliance with prescribed standards of child protection as well as care and support;
- various research reports from USAID, PEPFAR, Plan International, HelpAge International, Horizon Population Council, World Vision, JLICA and the HSRC; and
- reports from Regional Inter Agency Task Team (RIATT-ESA) and Stephen Lewis Foundation conferences on the challenges faced by older caregivers.

These documents articulate, not only the goals, policies and strategies that countries are required to adopt and have adopted, but also bring to light challenges that have been faced and lessons learnt in fulfilling these obligations. As such, they constitute a valuable repository of experience that can be harnessed in order to improve the care and support provided to children in households headed by older caregivers.

3.3 Research methodology - Older carers

The field research for old carers was conducted by HelpAge International (HelpAge) partner organisations in the countries of Ethiopia, Kenya, Mozambique, Uganda, South Africa, Zambia and Zimbabwe from September 2009 to June 2010. A total of 256 older carers of children orphaned by AIDS participated in the focus group discussions (FGDs). The total number of older women carers was 133 and the total for older men carers was 123.

The older carers were selected by the HelpAge partner organisations. The focus group discussions were also facilitated by HelpAge partner organisations which had previous experience in organising and conducting FGDs. HelpAge developed guidelines and lead questions for the focus group discussions in collaboration with the partner organisations. A semi-structured questionnaire was used to collect demographic and socio-economic information from each of the participants. The workshops were all conducted in the older carers' home languages. All the discussion in the workshops was recorded, and then translated and transcribed into English. These transcripts formed the data and were subjected to thematic analysis. Three separate focus group discussions were held for males, females and a combined group in each site.

The FGDs sought to find out about the difficulties and challenges faced by older caregivers such as dealing with sexuality issues, handling discipline, psychosocial issues and disclosure of a parent's death plus types of support they receive, lessons learnt and recommendations for the future. The older carers represented those living in both rural and urban areas.

3.4 Research methodology - Children living with carers

The research with the children did not use a conventional focus group approach using rather a child-centred participatory approach that took into account the age and stage of development of the children. A set of widely accepted guidelines on research with children were applied (Schenk and Williamson, 2005) and the University of the Witwatersrand Ethics Committee (South Africa) approved the principles and methodologies of the research approach and workshop activities.

A child-centred participatory approach is one in which children take part in a set of activities to “construct a representation of their social world” (Woodhead, 1998: 22). Once this has been done, the researcher is then able to ask about the topic of interest within the context of the representation.

Research with the children was undertaken in Ethiopia, Kenya, Mozambique, South Africa, Tanzania, Uganda and Zimbabwe through RIATT-ESA and HelpAge partner organisations. In each country an urban and rural site was selected and two separate groups were held with 12 children (six boys and six girls) in two different age groups (10-13 and 14-18). In Kenya the local organisation worked only in a rural area so research was done only in a rural site. In South Africa the local organisation worked only in an urban area so work was done only in urban sites. Note that the data from Tanzania was drawn from a study conducted in 2008 that has been presented in a report published by the KwaWazee Project (<http://www.riatt-esa.org/resources/living-our-bibi-qualitative-study-children-living-grandmothers-nshamba-area-north-western->). The data from the KwaWazee study was gathered through a very similar set of activities to the research conducted here.

A total of 261 children aged between 10 and 18 who had been orphaned by AIDS and living with older carers participated in the research workshops. Descriptions of the nature of the households in which the children were living are described in the findings below.

Children participated in a number of different activities over a full day. The day began with games to help the children relax. The games were followed by a number of different activities. These activities all involved discussion. The full-day workshop allowed the children to gain trust in the researchers and confidence in talking about their lives and concerns. The workshops were all conducted in the children’s home language, which the support facilitator interpreted for the researcher. All the discussion in the workshops was recorded, and then translated and transcribed into English. These transcripts formed the data and were subjected to thematic analysis.

Children worked on drawing activities they do in a day, the problems they face and their ideas for interventions to help them. One of the most effective activities was one where children identified the many different kinds of work they did in a

week. They grouped this work, using drawings and large chalk circles drawn on the ground, into household work, work to earn money and work to look after grandparents. They then reflected on the different kinds of work they did. This activity allowed the children to talk about both the negative and positive aspects of the work in detail.

Use was also made of paper figures that allowed us to discuss difficult issues like discrimination from community members, difficulties in the relationship with grandparents and school progress in the third person.

Ensuring responses are not influenced by the researcher

An important principle in any research is to avoid 'experimenter error'. In qualitative research this implies using techniques and tools that allow respondents to describe their own experiences in as unedited a way possible.

One of the important principles applied in this research was to make sure that the researcher did not lead the children in any way – to avoid putting words into their mouths. Care was taken to give non-directive instructions when introducing activities. The activities themselves were designed to be open-ended so that they did not preempt the children's responses. Questioning during the discussions was kept to initial open-ended questions and then to questions of clarity. In this way we made sure that what we were collecting was the children's authentic experience.



Figure 1 - Children describing their household drawings



Figure 2 - Children's drawings of problems they face in their day



Figure 3 - A child showing with a leaf the kind of work he likes to do – in this case cooking. “Because when you are cooking it means there is food to eat.”

3.5 Data analysis

All of the discussion in the FGDs with older carers and the workshops with children was recorded. It was then transcribed and translated. These transcripts formed the data that was then analysed.

Data from the older carers’ focus group discussions and the children’s discussions in research workshops were analysed by using a rigorous thematic analysis. Thematic analysis is described here as: *a process for encoding qualitative information. The encoding requires a specific ‘code’. This may be a list of themes ... A theme is a pattern found in the information that at the minimum describes and organizes possible observations ... Themes may initially be generated inductively from the raw information or generated deductively from theory and prior research (Boyatzis, 1998:vii).*

The themes into which the research findings were organised were generated inductively from the raw material. This means they were allowed to emerge through reading and rereading the data. It is important to note that a theme was agreed to have ‘emerged’ if it was an idea expressed by the majority of the participants in a group and then across the groups in different sites. This was made possible by the rigorous encoding of the transcripts. Where a ‘voice’ was heard against the common pattern this has been reported in the findings, often with reflection on why this difference was there.

3.6 Limitations

One of the limitations of the research was that we were unable to work with the actual children of the older carers who participated in the focus group discussions in each site. This was largely because we used different partners in some of the countries for the children and the older carers research. In spite of this, there is remarkable congruence between what the children and the older carers say.

Another limitation is that the research did not include a rural and urban site in each country. Issues in urban, rural and peri-urban contexts can often differ and therefore general conclusions drawn from research which only took place in one of these contexts need to take this into account.

In addition, many of the older carers have been previously involved with various support programmes being implemented by HelpAge partner organisations. This might have influenced their recommendations on the types of support they feel is most important to fulfil their role as caregivers.

4. Findings

4.1 Review of literature - Summary of findings

The literature review was structured around the following issues:

- Role of older carers in raising children orphaned by AIDS;
- Intergenerational relationships;
- Children's communication and participation in intergenerational relationships;
- Social support mechanisms that mitigate intergenerational gaps for both older carers and children; and
- Policy and programme gaps and lessons learnt.

The literature reviewed on the role of older carers in raising children orphaned by AIDS emphasised the need for a rights-based approach built on the Convention on the Rights of the Child and the African Charter on the Rights of the Child. Two rights were especially identified as stress points that challenged intergenerational relationships in older-headed households: the right to health care and the right to psychosocial support.

Research shows that older carers need clear information about HIV infection, transmission, symptoms and treatment. They also need information about child illnesses and available health services. Also, older carers need to listen to children's concerns and be able to inform, educate and reassure them in language and terms they understand. Supportive counselling or psychosocial support is a necessary support for older-headed families to help the children address their emotional and psychological trauma positively and with understanding.

Intergenerational relationships refer to arrangements that arise when members of two different generations are bound together in a common household. In the case of older-headed households the two generations are even further removed from each other by the loss of the parents, often referred to as skipped-generation households. Some major challenges for these skipped-generation households identified in the literature are:

- **Grief and trauma** - older caregivers experience distress due to having lost one or more adult children;
- **Incapacity /unpreparedness** for the demands of parenting;
- **Physical infirmity** - World Vision (2005) found that 37% of older carers succumbed to poor health once they had embarked on giving care;
- **Poverty and a lack of regular income** - children living in older-headed households are poorer than children living in households with a parent(s)

(Clacherty, 2008) - regularly going hungry, not having enough clothes, not having any soap with which to wash, and no bed linen and blankets;

- **Inaccessible health care** - distance to health facility, cost of transport, treatment and attitude of health workers complicates older carers' and their children's access to quality care at health facilities;
- **Access to education** - children living with grandparents are less likely to attend school, and often miss or drop out of school mainly because of poverty.
- **Child exploitation and child rights abuses** -grandparents can be forced to resort to exploitation of their grandchildren to generate an income – the literature has examples of early marriages so that families can access a dowry, as well as child labour and begging.
- **Access to documentation and registration** - older carers do not appear to be well-informed about the importance of birth registration, resulting in a tardiness in pursuing access to birth certificates and related enabling documents (UNICEF 2008). With no legal identity, children may be deprived of family inheritance, assistance and protection. Without adequate documentation, older caregivers are also unable to access limited social protection schemes that are available.

However, despite these challenges there is strong evidence of the positive aspects of skipped-generation households. Even when coping with these challenges, UNICEF's 'Voices of the Children' project found that children preferred to be talked to and prepared for future life by older people. Talking to older carers minimised their worries and enabled them to make informed decisions about whether or not to have sexual relations before marriage. Children prefer to live with their grandparents after the death of their parents rather than other relatives. They feel that their grandparents provide more love and affection than other relatives (International HIV/AIDS Alliance 2004).

Literature reviewed on communication and participation of children in intergenerational relationships focused on:

- **Conflict relating to discipline and the rights to play and rest** - older caregivers would like to raise children in the same way they raised their own children, namely, with strict, authoritative rules and without taking generational differences into consideration. This approach has the potential of leading to misunderstanding, and even estrangement, between them;
- **Consequences of poor communication** - effective parenting and communication skills are needed that would enable older carers to motivate the children to talk about their feelings and participate in the management of their lives.

The literature review examined the following social support mechanisms that mitigate intergenerational gaps for both older carers and the children they care for:

- **International policies and frameworks** - CRC, CEDAW, Madrid World Assembly on Ageing, UNGASS 2001. Indicator 10 'Support for Children Affected by HIV and AIDS' needs to be unpacked in order to target older caregivers and the children they care for;
- **Regional policies and frameworks** - 2008 African Union adopted a Social Policy Framework;
- **SADC Strategic Framework on OVCY** and minimum package of social protection services and psychological support services and support to caregivers of orphan children;
- **National policies and frameworks:**
 - **National Policy or Strategic Framework for OVC**-Ethiopia, Kenya, Malawi, South Africa, Tanzania, Zimbabwe and Uganda. Note that Uganda is the only country to include the needs of older caregivers;
 - **National HIV and AIDS policy** with reference to support to older carers and children: Ethiopia, Mozambique, Tanzania, Zambia and Kenya;
 - **Social protection – social cash transfer programmes for orphans and caregivers:** Kenya, Malawi, Zambia, KwaWazee, Tanzania;
- **Civil society, international aid agencies and NGO interventions** - PEPFAR, Save the Children, HelpAge International, Action for Children in Uganda, Circles of Care, KwaWazee;

Policy and programme gaps and lessons learnt were a key aspect of the literature review and included:

- **Country orphan and vulnerable children policies are silent on older caregivers-headed households** - however the situation is more positive in relation to the national HIV and AIDS strategies of Ethiopia, Kenya and Mozambique;
- **CSO Innovations have not been scaled up nationally** - state officials cite a lack of resources as their major handicap. CSOs assume the bulk of the responsibility for, and take the lead in, children and older caregiver care and support work;
- **Orphan and vulnerable children solutions remain project-based** rather than integrated into national policies and programmes;
- **Older caregivers remain invisible in policies** – there are no adequate social protection systems in place to ensure their well-being;
- **Cash transfer schemes – getting to the root of the problem.** These are emerging as a successful strategy for mitigating many of the challenges faced by children and older caregivers. Examples are South Africa and foster care grants and child support grants, Kenya's national OVC cash transfer programme and Botswana, Namibia and Lesotho which provide social pensions for older people. The KwaWazee Project in Tanzania provides pensions to the poorest older-headed households.

The full version of the literature review, undertaken by Patricia Martin and Andre Wiesner in November 2010: *An Analysis of Intergenerational Issues Between Older Caregivers and Children in the Context of AIDS: A review of the challenges, obligations and the way forward* can be accessed on <http://www.riatt-esa.org/>.

4.2 Findings – Research with older carers

The findings of the FGDs with older carers are presented under the following emergent themes:

- Theme 1: The nature of the households;
- Theme 2: Perceived role of older carers in caring for children orphaned by AIDS;
- Theme 3: Difficulties older people face as caregivers;
- Theme 4: Dealing with sexuality issues;
- Theme 5: How caregivers handle discipline;
- Theme 7: Handling psychosocial care issues: Stigma, stress and depression among the children;
- Theme 8: Dealing with disclosure of parents' death;
- Theme 9: Comparison with raising own children;
- Theme 10: Challenges faced by caregivers in providing care for children and ways they try to solve these;
- Theme 11: Lessons older caregivers learnt in caring for children; and
- Theme 12: Recommendations from older carers for future support.

Please note that in this section:

- Children orphaned by AIDS are referred to as children and not 'OVC'.
- Reference to discussion from gender-specific groups specifies if an older woman or an older man said it, ideas from mixed gender groups are referenced by the term 'older carers'.

Theme 1: The nature of the households

The majority of carers were engaged in small-scale farming or petty trading and were members of some social support group. The average age of the older carers was 65 and the average number of children being cared for by older carers was three. For example, in one of the Kenyan groups the total number of older carers who participated in the focus group discussions was 23 (12 older women and 11 older men carers) and they cared for 78 children (47 male and 31 female children). Seven male children and four female children were living with HIV and AIDS. The older carers were also caring for six male adults living with HIV and AIDS.

Theme 2: Perceived role of older carers in caring for children orphaned by AIDS

Older carers in the majority of the 21 focus group discussions in the seven countries stated that providing basic needs for children under their care was the major role they played as caregivers. Basic needs included food, shelter, clothes, education and health care. Another role mentioned by older men in Uganda was training children in proper hygiene. Providing school materials and paying school fees were stated by older women in Uganda and older carers in Zimbabwe.

FGD participants cited the role of providing guidance and counselling for children to be good citizens by encouraging them to be disciplined, respectful and responsible people, teaching morals and ethics, not to behave badly in schools and other places. Teaching children cultural norms and values were also mentioned by older men and older carer participants in Uganda.

Other important roles related to life skills, stated as introducing children to farming and small scale business, care for livestock and domestic work, showing them love and affection and being mother and father to the children. Meeting emotional and spiritual needs of the child such as religious mentorship was cited by older carers in one of the Kenyan groups.

Providing financial support and security were mentioned by older men in Uganda. Other responses from older men were that older men fulfil their role as caregivers with the help of aunts (older men in South Africa), and they are sometimes assisted through remittances by relatives who work in South Africa (older men in Mozambique).

Theme 3: Difficulties older people face as care givers

Older carers at every one of the 21 FGDs indicated that parenting issues, and lack of income and resources were the leading difficulties in fulfilling their role as caregivers. Other major difficulties were physical and mental weaknesses, lack of social, community and family support, stress and depression and lack of agricultural inputs.

Specific parenting issues included:

Dealing with rivalry and discrimination -This related to rivalry among children orphaned by AIDS and other children in the household, and included inadequate sleeping facilities and petty jealousies (older women in Zambia). A factor mentioned by older men in South Africa and Uganda was the difference in the upbringing and family background of the children who become members of the household. There can be discrimination by other members of the household

including helpers of older caregivers according to older carers in Uganda who also stated that children think they are not supposed to be cautioned or blamed because they are orphans.

Behavioural, emotional and psychological issues - Older women in Zimbabwe stated that they are unable to address the psychological needs of the children. Older men in South Africa claimed that children are very demanding, with alcohol and drug abuse being high, and the children refusing to listen to them saying they are not their fathers. Another example cited by older men in Ethiopia is misbehaviour of the children, not doing their school work properly and not accepting instructions or advice given by the older caregivers. Older men in Uganda stated that children between the ages of 15 and 18 tend not to agree on certain things, especially in regard to discipline and caution, while those between the ages of 5 and 9 tend to be obedient to the grandparents.

Stress and depression also manifests themselves in various ways. According to older men in Zambia, they agonise about the survival of the children affected by AIDS and they suffer from high blood pressure, stress and depression as a result. In addition, they worry about whether resources will be available for the children to complete school, the adverse influence of peer pressure, defiant behaviour they cannot handle - and for girls - they worry about early pregnancies.

The older men admitted they were traumatised by the death of their own children and they are at a loss as to how they will take care of them without any financial means. The sadness and depression experienced by the children when remembering their deceased parents are major challenges cited by older carers in Ethiopia. Caregivers feel frustrated because, *"Our best is not appreciated by the children. We are stressed because we worry about the welfare of children and this leads to high blood pressure"* (older carers in Zambia). Also contributing to their stress is the fact that they had to care for their own children and now their grandchildren (older men in Uganda).

Financial, inheritance issues - A major difficulty cited by older carers was lack of income and resources, and its impact on education and health. Children not accepting that the caregivers do not have the same means as their parents, and constantly reminding the older caregivers that if their parents were there they would not be in such a situation, were cited by older women in Zambia and one of the sites in Kenya. Lack of time to engage in productive work due to caregiving contributed to financial pressures according to older women in Zimbabwe.

Another recurring impact cited by older carers at nine FDGs was that they are not able to provide for their basic needs to feed, clothe, educate and meet the health needs of children under their care, and fulfil their caregiving role because of limited sources of income. They are not able to feed the children properly and they worried this was affecting the children's growth and development. Older

men in Zambia cited the lack of support from their surviving sons and daughters as a difficulty and the need to borrow money to make ends meet, while older carers in Uganda stated that children are exposed to hard work at an early age in an effort to help the household meet its basic needs.

Older carers at four FDGs cited lack of income and its impact on education including the inability of older carers to send the children to school and pay for secondary education. In Mozambique, older carers said there is a lack of secondary schools, which are often far away, and therefore money is needed for boarding. Shortage of money also restricts older carers from seeking health care for the children and themselves, as well as not being able to buy prescribed medicines. Long distances and inaccessibility to public health facilities, and insufficient medication and health care in the public health units, were other health-related difficulties cited by older women in Uganda.

Another problem discussed was related to inheritance. Problems arose when sharing the estate, between their grown up children and the younger ones they were now caring for. Another issue raised by older women was that the families' heirs wanted to drive them out of the homes of their late husbands and this interferes with their caring role and causes great stress.

Other difficulties included:

Physical and mental weaknesses, being too old and frail to care for the children, generating income and mobility problems make it difficult to undertake agricultural work.

Lack of social, community and family support from various partners, government, NGOs, community members and relatives. The community does not care about the children who are orphans, according to older women in Uganda, who also cited interference by the community and neighbours, influencing children to do contrary things which "divert them from the right way you want them to be".

Some partners like civil society organisations or local government give support to only a few family members, mostly targeting orphans and vulnerable children, which creates conflict, discrimination and disharmony in the household according to older men in Ethiopia.

Misunderstanding between caregivers and weak parenting skills - Older women in Uganda cited misunderstanding between the older husband and wife caregivers of the children as an issue. Older men in Uganda felt that "weak home administration" like permissiveness among the care givers themselves was a problem.

A lack of agricultural inputs such as seed and fertilizers and access to markets for agricultural products were mentioned by older men in Mozambique and older carers in Zimbabwe, along with the impact of drought, causing food shortages.

Theme 4: Dealing with sexuality issues

The main way older carers deal with issues of sexuality with children under their care is by resorting to traditional beliefs, discussing risks of unprotected sex and early marriages, abstaining and limiting the number of sexual partners, frankness about the risks of contacting sexually transmitted diseases and HIV, respecting others, responsible living, through providing guidance to girls on bodily changes, and using storytelling to discuss sexuality.

The traditional beliefs on sexuality mentioned by older carers are that, as part of social standards, girls are educated by older women and boys by older men. According to older men in South Africa, female children are not left in the care of older men, but they are taken care of by relatives, as there are worries of potential child abuse by uncles and older men. Women carers in Uganda and Zambia stated that every culture has ceremonies representing a rite of passage and older carers have a responsibility to tell children why cultural ceremonies are conducted. Older men in western Kenya stated that men are aware of the benefits of male circumcision in the prevention of HIV and AIDS and, although the Luo ethnic group is traditionally a non-circumcising community, they allow their boys to have it done. Older men in South Africa also mentioned that circumcision is not a Zulu tradition, but the government has called for men to be circumcised as a preventive measure for HIV. Older women in South Africa admitted that sexual practices have changed and what was practiced when they were younger is no longer done.

Storytelling is an example of a traditional practice in providing instruction on discussing sexuality. Older carers in Zimbabwe said they sit down together with the children and reflect on how they taught their parents to be good citizens. However, older men in Mozambique complained that their efforts are undermined by what young people are exposed to through the media and peer pressure. They also added that if older men are staying with a girl child, there is no choice; they have to explain issues of sexuality especially by giving concrete examples of HIV and AIDS. The older carers felt that the pandemic was changing the social norm of older women teaching girls with older men now also teaching the girls. Creating a good interactive environment to facilitate discussions at home was something older men from Zimbabwe hoped they encouraged. Older men in Uganda also mentioned that it was important that the children feel they are members of the family and talk to them with love and care.

Discussing the risks of unprotected sex and early marriages are important ways older carers communicate with children on sexuality. Older carers in Ethiopia said they discuss the side effects of unprotected sex and multiple sexual partners in contracting STIs and HIV and AIDS, and how HIV and AIDS is very serious and brings miserable impacts on their lives and their families. Older carers in Uganda stated that they talk to the children about the risks of unprotected sex, premarital sex, contracting HIV and AIDS, early pregnancies and being prepared for parenting. *“You have to show the boys and girls the risks of getting involved in matters of sex before getting married,”* according to an older man in Uganda, while older men in Zambia advise the children not to succumb to peer pressure, warn young girls the dangers of being compromised by the opposite sex, to guard against situations which could lead to “defilement” and not to accept gifts from strangers.

Abstaining from sexual behaviour and limiting the number of partners were other key messages. Older carers in Ethiopia advise children to be patient and give due attention to their education, which will enable them to be self-reliant once adults. In Mozambique older carers said they tell girls to wait for their time, not to go after boys and be careful of STIs and HIV and AIDS. For the boys they advise them to live a straight life, pursue school work and *“not give pregnancy to girls”*. Limiting the number of partners was mentioned by older women in both Mozambique and Kenya. An older woman carer in Kenya said, *“I boldly tell him to have only one girl friend and go for VCT”*. Female caregivers in Kenya contended that it is not wise for female caregivers to leave the burden of talking to boys to the male caregivers. One said, *“We must talk to them when we notice them going astray”*.

Frankness in discussing sexuality and HIV and AIDS was cited in several focus group discussion sessions. Older women in South Africa said with HIV and AIDS infection, older people have learnt not to be shy to talk to children about sex. According to an older women in Kenya:

I do not consider that there is anything so sensitive not to be talked about with orphans. This is a habit of the past. Because of AIDS, there is no need of hiding anything from children, they must be told.

A women carer in Uganda claimed that she takes children to visit people living with HIV and AIDS, then after the visit she asks them for their observations and interpretation of the situation.

Instilling respect for others and living responsibly were felt to have a direct effect on sexual behaviour. Older carers in Mozambique, Ethiopia and Zambia indicated that they counsel children to respect older people and teachers and to live with dignity.

Bodily changes offer an opportunity for older carers to discuss issues of sexuality. The children are encouraged to open up when they experience any bodily change and need help or guidance. The girl child can “*easily speak about their feelings, unlike the boy child*” according to an older woman in Uganda. An older women carer in Zimbabwe said:

I discuss with girls often on issues of puberty and adolescence. I always keep a check or inspect the girl to see if there are other developments taking place when she is growing up. This discourages her to have early sex as I can quickly detect it. I show the growing girl the best way to prepare her sexual organs as she prepares to grow up into full womanhood.

Sex education taught at school has some impact, such as understanding puberty and the menstrual cycle, according to older women in South Africa.

Dealing with teenagers was cited by older carers in Ethiopia and Kenya as a challenge. They explained that the children act as if they know everything, and most of them do not positively accept the advice given by grandparents, especially, at the time they reached teenage years. The children are very disobedient and do not understand the limiting condition of their caregivers. Such children keep to themselves and are not ready to share their problems. Women older carers from Zambia indicated that they find it difficult to talk to male children on sexuality. At puberty and adolescence, teenagers become difficult and do not accept advice from caregivers.

Communicating with children involves a lot of pampering according to older women in Uganda. The kind and depth of the discussion between the child and the caregiver will depend on the personality and knowledge of a child on sensitive matters such as sexuality or drug use. Ten out of the 11 older women in Uganda agreed that the girl child is easier to talk to and care after. They added that girl children easily respond to caution and that when they get married, they still support older caregivers. Older men in Uganda said that sexuality is usually handled by older women or relatives like aunties, but they do advise the girls to be responsible people. According to older carers in Zimbabwe, older men are afraid of talking about the issue of sexuality with girls in detail.

Theme 5: How caregivers handle discipline

The main ways mentioned at focus group discussions on how older carers deal with discipline were corporal punishment, discussion, tolerance and being supportive, done jointly with other family members and teaching children to respect others, practice good morals, avoid bad behaviour and using traditional ways.

A defining factor regarding discipline according to older carers is the age of the children. An older woman in Mozambique remarked that, *"We try to counsel them. They listen when they are still young, but they become stubborn as they grow which makes it difficult for us to understand each other"*. Older women in Uganda stated that children between the ages of 15 and 18 tend not to agree on certain things, especially in terms of discipline and caution. This was confirmed by older carers in South Africa who said that young children are much better to deal with, but teenagers are very difficult especially when they abuse alcohol. Older carers also said as older people they are threatened by the teenage children, and they are very arrogant and abusive. Older carers in Ethiopia stated that as children reach teenager age they act as if they know everything, do not easily accept families' advice, start to pass most of their time with their peers, start sexual relationships with peers, and complain if they are not equally treated like other family members.

Older carers in the focus group discussions indicated that they use **corporal punishment** as a way of disciplining children. However, it was a last resort after talking with the children. One older woman in Zimbabwe said that, *"The first option is discussion, if this fails then I advise other close relatives and if this fails I use the rod or whip"*. Older women in Zambia and Zimbabwe shared that they talk to the children to establish why they misbehaved and, if necessary, they are whipped. Older men still believe in corporal punishment but older women are protective according to older carers in South Africa. One related form of corporal punishment by older carers in Ethiopia was reducing what was normally provided to the children like clothes, better food and school materials. One reason for this approach was given by older carers in Ethiopia; that they handle discipline issues through cultural practices which they inherited from their parents.

On the other hand, other approaches cited towards discipline were **discussion, tolerance, respecting others, good morals and being supportive**. An older carer in Zambia described it as, *"we first start by sensitising them of what is expected of them as they come join us and we try to make them understand our situation and behave accordingly. However these children are very difficult to discipline"*. Talking to the children in a friendly manner and telling them that they are the children's helper is an approach taken by older carers in Kenya. Older men in Mozambique said that they firstly acknowledged that being disobedient can sometimes be normal for children. Older people counsel the children but they hardly obey.

Older carers in Mozambique indicated they educate children on good morals such as greeting and respecting others, and receiving visitors, which promotes good behaviour and helps stem the need for disciplinary action. Older women in Kenya explained that they first teach how to love one another and how to respect people in the wider community. For children who follow each other by birth, the

younger ones should be taught to respect the elder ones to reduce the tendency of natural rivalry amongst them.

Caregivers must also have self-discipline before they can talk about instilling discipline in the children. Most importantly, treat all the children under your care equally. As parents, it is important to lead as good examples in everything they do. They should treat all the children as theirs and show equal love for all. A caregiver must take immediate action on any issue that the child brings. Older carers in Ethiopia advised that there should be no occasion where a caregiver supports or takes side with the child when the child has made mistakes.

Older carers do call on other family members to assist them with disciplinary issues. Older women in South Africa explained that discipline is done together with other extended family members, while older women in Zambia indicated that for boys they ask for the assistance of a male relative or other elder in the community. Older carers in Ethiopia indicated that they discuss with teachers the behaviour of the children under their care.

It is interesting that older carers admit there is a **bias on the girl child** because she is the exemplary figure of the home and she therefore must be highly disciplined. An older woman in Uganda stated it as, *“All the children are equally groomed to become responsible adults, but emphasis is put on the girl child because they are expected to become role models to their children”*. This was mentioned as well by older men in Uganda who agreed that the girl child should be given more guidance on issues of good behaviour. They also contend that she is the disciplinarian role model of the family.

A change from the past for older carers is the issue of **child rights**. Older men carers in South Africa claimed that children are quick to point to their rights and older people subsequently felt helpless as there were no children’s rights recognised in previous generations. Older carers in South Africa said that with children’s rights it is very difficult in general to discipline children in the way that you use to discipline your own children.

Peer pressure and external influences were mentioned by older men carers in Mozambique. This is because of the effects of television, radio and the generational gap between them and the children. They said the children now see them as irrelevant.

Theme 6: Abuse of children

Sexual abuse of children was identified as a serious issue. There is a lot of sexual abuse by uncles and neighbours according to older women in South Africa. An older woman in Kenya stated that an orphan was raped by the uncle, but that he was arrested. In Kenya older women claimed that as a girl child grows up the grandfather can start to engage in sexual relations with her and the

community ultimately learns about it. The girl is not given any guidance on sexuality and she takes it as “playing”. Older people do not report incidences of sexual abuse because they are afraid of shaming the family according to older women in South Africa.

Physical abuse was another form of child abuse identified in the research. An example from older women in Kenya was of an older man marrying a second wife after his first wife passed away, and the second wife mistreated and battered the children which were being cared for by the older man. Another form of physical abuse is **domestic child labour** where children are overworked with tasks such as fetching water, housework, involvement in agriculture and animal husbandry which adversely affects their ability to do homework, socialise and play with other children.

Theme 7: Handling psychosocial care issues: Stigma, stress and depression among the children

Psychosocial issues are a major concern for older carers. The nature of the psychosocial issues varied depending on the age of the children. Fear of the death of the older caregiver, loneliness and depression were cited. Other major factors mentioned by caregivers were poverty and the inability to provide basic needs as underlining causes of psychosocial issues.

Regarding the dynamics of **psychosocial issues and the age of children**, older women in Uganda stated that children tend to isolate themselves especially between the ages of 13 and 15 years. Older carers in Kenya claimed that psychosocial issues they have to deal with in younger children are related to their inability to express their needs. Such children find it difficult to report their problems to caregivers.

Poverty, inability to provide basic needs and the impact on psychosocial issues were stated by caregivers. Older carers explained the main problem is poverty. In Mozambique, older carers claimed to have had a lot of resources, but availability of these resources has since diminished. Older carers in Uganda said the lack of basic needs leaves children with the feeling of deprivation. Older women carers in Uganda also shared that the inability to effectively be provided for is attributed by children to the fact that they are now no longer able to live with their parents as a result of their death. When their parents were alive the issue of basic needs was not as great a problem. There is also a psychosocial impact on older carers who worry about food to feed the children, about their own death and what will happen to the children. In Zambia, older carers worry

that the girl child would turn to prostitution if they are not able to provide for their needs.

Fear of caregivers dying, loneliness and depression were major psychosocial issues identified. Older carers in Uganda explained that the psychosocial issues with which older carers were confronted involved fear by children of being left alone to cope in the case of the death of their caregivers and feelings of isolation. Older men carers in Uganda also said that children think they are deprived because their parents died, and this has an impact towards work. One carer in Uganda explained, *“When you send them to do something, they respond reluctantly”*.

Older carers in Ethiopia said that depression is common, particularly for the children who knew their parents before they died. This condition increases as children grow up and reach their teenage years. In South Africa teenagers experience a lot of problems and are often very depressed according to older men. They claim there is lack of social facilities, and abuse of drugs and alcohol is prevalent. Older men in Uganda believe that discrimination by fellow children who tell them that their parents died can have an adverse impact. In Kenya older women observed that children in such situations get “jittery”, do not want to be sent outside the household pretend to be ill, become thin and, in extreme cases, they attempt suicide.

In responding to psychosocial issues older carers in Mozambique stated that they monitor the children to see if there are any gloomy moods. If there is a problem the carers respond by counselling. Older carers in Uganda indicated they try to counter the issue of loneliness and depression by providing a sense of belonging and security for the children.

Theme 8: Dealing with disclosure of parents’ death

Disclosure of the cause of death of children’s’ parents is a critical psychological issue which older carers have to confront. Older carers who said they have disclosed the death indicated that it is a gradual process which involves a lot of communication, love and openness, depending on the age of the child and the prevailing situation. However, some older carers stated that they in fact do not willingly disclose how their adult children died. Other reactions from older carers varied from indicating the importance of telling the truth, to relying on traditional ways and practices to deal with disclosure to children hearing about how their parents died from friends and peers.

Older women in Kenya who **disclosed the cause of the parents’ death** said they did so only when they were sure the child would not be psychologically affected, and that disclosure of the cause of the parents’ death requires taking sufficient time. Older carers in Mozambique commented that they reveal the

cause of the parents' death only to mature orphans. Older women in Uganda indicated the process of disclosing involved giving a related story or information about the cause of death. An example was related by older carers in Kenya that in their village there was one orphan who did not know his mother was dead. He was sad and refused to eat at home. He also threatened to take his life.

Older carers said it is good to tell the children the truth. An older woman carers in South Africa was very straightforward in stating that, "*The fact remains death is natural, whether due to HIV or not*". There was a similar response from older men in South Africa. One man explained that, "*most people die of AIDS, it is not something new or to be ashamed of*". Older men advised to simply tell the truth, even if it means revealing that the parent died of AIDS. Disclosing the cause of death as AIDS helps children to understand the dangers of HIV and AIDS.

There are older carers who chose **not to disclose willingly** the cause of death of the children's parents. Older carers in Zimbabwe commented that children are affected deeply by terminal illness and subsequent death of a parent or sibling. One carer claimed:

We remove children from the home after death has occurred without notifying them of it. We assume they will know it from others and we leave it to fate. Children will know of the death after burial when we show them the grave.

Older carers admit that disclosure is important but asked '*How do we tell them?*' The way they tell the child does not heal or lessen grief and there are no clear ways to address stigma which follows. Women carers in Zimbabwe said that when a parent dies in hospital they tell the children that their parent went to a far away city and the date of return is unknown, while older women in Zambia added that they found it difficult to tell the children that their parents died of HIV and AIDS. Some of the children have come to find out through gossip. In Kenya older women indicated that they do not disclose that the parents died of HIV and AIDS unless the children ask. Older men in Uganda claimed that children are generally not informed about the cause of the death of their parents, but they discover it on their own or are told by friends and peers.

Older carers in Zimbabwe described the **traditional way the death of the parent is dealt with**. Older women carers said that children are not told of the death, but they are sent away to neighbours or relatives homes and will only be shown the grave a day or two after the burial. Older men stated that the culture is changing and some families are allowing children to view the corpse.

Theme 9: Comparison with raising own children

Older carers were asked about the greatest differences between caring for their own children and the children now under their care. Three main differences were described in the focus group discussions: a lack of income and increased cost of living, physical effects of old age and the need to be more sensitive to the needs of the children.

A **lack of income** was cited as a major difference. According to older carers in Kenya, the biggest difference in caring for grandchildren compared to how they cared for their own children is that whereas the demands of today's children seem to be higher, the ability of older care givers has reduced. As one caregiver said, *"Back then we were energetic, economic inflation was not as high as it is today and during those days we had sources of income unlike today"*. Put simply by older women in Uganda: today income is meagre and sometimes there is no source of income. Older men in Uganda added that the availability and accessibility of resources is not easy and the burden of care for children has increased since they cared for their own sons and daughters.

The **increased cost of living** makes the provision of basic needs difficult according to older carers in Uganda. Older carers in Zimbabwe stated that family support is also limited due to economic challenges. An impact of limited resources is that children have to do more domestic duties because older carers can no longer carry out some of the tasks themselves, according to women carers in Zambia. A Zimbabwean woman added, *"Our children accepted our situation, but the children think that we have the resources when we do not"*.

Limited sources of income are also related to agricultural conditions which were mentioned by older women in Uganda. A Ugandan woman claimed that, *"The soils have become worn out and unproductive and crop pests have increased"*. An older man in Uganda said, *"the rainfall pattern has now changed for the worse"*.

Diminished and limited physical strength and frailness to care for children compared to the time when they were younger adults was mentioned by older carers in Uganda, Zambia and Zimbabwe. Older women in Zambia explained they looked after their children when they were young and energetic.

Having to be more **sensitive to the needs of children** was mentioned by older carers in Ethiopia, South Africa and Zambia. In Ethiopia it was described as the children needing more care and attention since they are very sensitive for even little things, and they also complain when remembering their parents. Older carers in Zambia said that they give the same attention to the children like they gave to their own children, however, with the children they have to be cautious in view of their situation.

Another difference cited by older women in Zambia was that children come from homes with different standards of living and discipline. A woman from Zambia explained that, *“With our own children we felt freer to discipline them, while with the children we choose our words carefully and we are cautious to criticise”*. Another dynamic identified by older carers in South Africa was that their children had love from both parents, unlike the situation today.

A change noted by older carers in Uganda is the nuclear family’s tendencies to limit people’s ability to help the children, unlike the past when the extended family had a collective responsibility. Moreover, there is now **no collective social responsibility** in raising the children and this makes instilling discipline difficult. Older carers in Uganda also noted the permissiveness of society now compared to when they were younger. An older carer in Ethiopia eloquently shared what most older carers must feel: *“Caring for the children is their responsibility and promise they took from their passed children, so they have to handle these children with high commitment, care and devotion”*.

Theme 10: Challenges faced by caregivers in providing care for children and ways of overcoming challenges

The main challenges cited in focus group discussions by older carers related to a lack of income and shortage of resources, environmental impacts and food insecurity, lack of access to health care, educating the children, stigma and weak parenting skills.

A lack of income and shortage of resources were major differences for older carers in once caring for their own children compared to children now. The impact is that older carers cannot cover basic needs like education, school fees, health care and clothes. Older carers in Ethiopia also commented that a lack of income means that they cannot engage in income-generating activities, and the high price of commodities such as food items is a challenge. Older women in Mozambique and Uganda said that the cost of living has increased but their sources of income are minimal.

Climatic changes resulting in drought and constant **food shortages** was cited by older carers in Mozambique, Uganda and Zimbabwe as major challenges. Older women carers in Zambia stated that they have inadequate food and usually only able to provide one meal per day.

A key challenge noted is **access to health care**. Older carers in Ethiopia, Uganda and Zambia lamented the distance of health institutions from their homes (e.g. accessing ART) and a shortage of money to cover transportation costs as challenges. Another health care issue highlighted in Uganda is drug supply. One Ugandan in the focus group claimed, *“There is no consistency in taking the drugs*

because they are not always available". Other older carers in Zambia talked about the high costs of medicine for children, particularly those above 5 years.

They also mentioned long queues at health service delivery points as a challenge.

Older carers in Mozambique and Zambia indicated that **educating the children** is a major problem, especially those in secondary schools (e.g. school fees, school uniforms, books). Another basic need which was identified by older carers in Zambia is **shelter** and the lack of money to sustain the expanded family as accommodation becomes a problem for the new arrivals. Living in crowded accommodation compromises the health of the children and has an adverse impact on their being able to do homework and socialise with other children.

Stigma was mentioned as a challenge by older women carers in Zimbabwe due to poverty, while older carers in Ethiopia said there was stigma and discrimination from community members, neighbours and teachers., even though, according to the older carers, the situation is improving.

Additional challenges stated by older men in Ethiopia and Zambia are **a lack of parenting skills** to handle the children including a lack of knowledge and skills in handling the children psychologically, dealing with health care and nutrition issues other than by using the culturally inherited ways of raising children. Transmitting good moral values to the children in spite of opposing forces from the media, was identified by older men in Mozambique as a challenge.

Misunderstanding between the children and caregivers as children grow up and reach teenage years was cited as a challenge by older women and men in Ethiopia. Caregivers believe children have developed bad behaviour, do not listen to caregivers and act as if they know everything. **A lack of external support** by different partners such as government, civil society organisations and community members was acknowledged by older carers in Ethiopia as a problem.

How caregivers overcome the challenges they faced

The main ways older carers face the challenges comprise undertaking small scale trading and engaging in income-generating activities, and seeking support from external sources and casual labour. Additional ways were mentioned such as using resources wisely, reducing food consumption, selling assets, borrowing money and remittances.

Small scale trading and engaging in income-generating activities were mentioned most by older carers in facing the challenges and burden of care in raising children orphaned by AIDS. Simple trading and selling vegetables were cited by older carers in Mozambique and Zambia. Income-generating activities such as brick laying and petty trading were mentioned by older carers in Ethiopia and Uganda. Older carers in Ethiopia added that children also join in.

Seeking external support was another way older carers address their challenges. This includes a variety of approaches such as developing close relationships with and asking for support from relatives, community members, civil society organisations, local government and well-wishers.

Carers also request advice from community members, children's peers and teachers. Older carers in Zimbabwe said this resulted in agricultural inputs being distributed by HelpAge Zimbabwe to help them withstand periods of drought. Doing piece work on farms, cutting poles and firewood, and making charcoal were examples of **casual labour** by older carers in Mozambique and Zambia.

Some other important ways identified by older carers were using the resources they have wisely, reducing the frequency and size of meals, buying clothes from second hand markets, selling assets and property, taking prepared and cooked food from various social events such as from funerals and rewarding the children for their good conduct and performances.

Types of supports received from various partners

Moral support was the only type of support identified by older carers which they received from **communities**. Caregivers in Kenya said that the reason they do not receive any support from their **peers** is because they have their own problems in caring for the large number of children orphaned by AIDS. However, older carers in Zambia explained that they share the burden through talking and learning from each other.

Various types of support are provided by **civil society organisations** such as supplementary feeding for the sick, educational support, income-generating activities, shelter repair, farm input support, home-based care and psychosocial counselling. Older women in Mozambique cited the support by the national CSO, Vukoxa - a consortium for street children - which gives them clothes and agricultural inputs like hoes, seeds and water pumps to enhance their production. The extremely vulnerable older people receive food rations from the harvest of the association Vukoxa's field. Vukoxa also assisted in acquiring birth and poverty certificates for the children and sensitised the community on children's rights through the work of activists. Older women in South Africa and Zimbabwe identified similar types of support as well as social protection programmes like cash transfers.

A major form of support provided by civil society organisations was related to **education** and, in particular, supplementary feeding programmes and provision of school materials like books, pens, uniforms and school fees. School programmes such as peer group education and counselling were mentioned by older carers in South Africa. Another school programme assisted intergenerational relations, according to older men in Mozambique, by telling

children to respect older people in the communities. However, an older carer in Kenya claimed that, *“There is nothing the school does other than treat orphans like any other child. If it is for lack of fees, the school chases away all the children”*.

Some support by **government** was mentioned by older carers such as school clubs supported by the Ministry of Community Development and free medical services in Zambia. Older carers in Zimbabwe said the government used to provide support to children through the Basic Education Assistance Module (BEAM) Programme, but have since stopped. Older women carers in Zimbabwe added that the government is not doing much but wants their support in the form of taxes.

Theme 11: Lessons older caregivers learnt in caring for children

Two main lessons learnt were identified by older carers which they wanted to share with other older carers of children orphaned by AIDS. These are the need to **provide love and affection** and be **tolerant, patient and committed to their caregiving role**. Other lessons learnt include collaboration with external stakeholders; the importance of receiving training on parenting; and educating children as if they were their own. Older carers want to express that caregiving should be a collective effort and responsibility within the community. Problems experienced in caregiving should be shared with others.

There is also need for psychosocial support and seeking medical advice before the situation worsens; critically looking after and addressing the needs of chronically ill children; providing a balanced diet for children to keep them healthy and using finances wisely. Older carers in Mozambique, South Africa and Uganda said that caring for the children included **loving and treating them as their own**. An older woman in Zambia explained that, *“They are the future leaders and they may take care of us later on”*.

The need to be **tolerant, patient and to persevere** was highlighted by older carers in Zambia. An older carer said, *“We have become more resourceful, and have learnt to be patient and tolerant”*. Providing care for children is not easy and it needs a high level of commitment and patience according to older carers in Ethiopia. They also added that the children are very sensitive and need care, close supervision and love.

Maintaining close **collaboration and linkage with various development actors** to raise the issues and problems of children orphaned by AIDS are very important according to older carers in Ethiopia. Caregivers in South Africa said it was important to consult traditional courts in order to report domestic violence when it occurs. Older carers in South Africa and Kenya also stressed the importance of **joining support groups**.

Older carers also highlighted the importance of receiving **training on how to handle children's issues** in addition to what is inherited from past generations and experiences. Older carers in Mozambique advised not to give up educating children as though they were their own children. Caring for children orphaned by AIDS should be a **collective effort and responsibility** within the community according to older carers in Uganda. **Financial support for older caregivers** can be best provided by the government through cash transfers to vulnerable orphan and vulnerable children households according to older carers in Kenya.

Theme 12: Recommendations from older carers for future support

Three types of support were identified in focus group discussions as the most important in assisting older carers fulfil their crucial role as carers of children orphaned by AIDS. These are project support in the form of agricultural inputs; animal husbandry and income-generating activities and financial and technical support; and social pensions and cash transfers. Other support mentioned includes rights awareness training and paralegal advice, recognition by the community, government and other key stakeholders of their caregiving role and parental training, psychosocial support and support groups, and access to child grants and child sponsors.

The nature of the **project support** was access to agricultural inputs and animal husbandry. Older women carers in Uganda recommended support in income-generating activities. A specific project included food gardening by older women in South Africa. An older carer in Zambia said, *"We need financial farm input support so that we can sustain ourselves"*.

Financial and technical support were identified especially to cater for basic needs and to be able to provide school materials such as books and uniforms, and to afford sending children to secondary school. Older women and men in Ethiopia mentioned the provision of different professional support for orphans and vulnerable children by all relevant development actors.

The third major type of support cited by older carers was **social pensions and cash transfers**. Older men in Uganda recommended the introduction of universal social pensions for older persons. In Ethiopia, older carers also mentioned the need for sufficient and regular cash support which considers the current purchasing power of money to cover the basic needs of both children and older caregivers. Another form of cash transfer recommended by older women carers in Uganda is accessing sponsors for children under the care of older people.

Rights awareness training and paralegal advice were recommended by older women carers in South Africa. They talked about the importance of realising and respecting the rights of older people, their entitlements as citizens of the country and contributions made to society. Access to child grants was seen as one key

entitlement. Related to this was the need for attention and recognition of the caregiving role of older carers from various development actors, particularly government.

Parental training was identified as a need by older carers to effectively discharge their caregiving roles and counsel children. Also recommended was the need for older carers to become members of **support groups**. Older carers in Kenya emphasised the importance of older carers meeting to exchange problems and counsel each other. Older women carers in South Africa see this as a form of psychosocial support for older carers.

4.3 Findings - Children living with older carers

Notes about quotations

- i) researcher comments and questions begin with R;
- ii) a new child speaking is shown through the use of a new line;
- iii) quotes are identified in the following way:

(M) Mozambique

(E) Ethiopia

(U) Uganda

(Z) Zimbabwe

(SA) South Africa

(K) Kenya

(T) Tanzania

(R) = Rural area

(U) = Urban area

(OB) = Older boy 14-18

(YB) = Younger boy 10-13

(OG) = Older girl 14-18

(YG) = Younger girl 10-13

If a quote has (MROB) it designates a boy aged between 14 and 18 in a rural area of Mozambique.

- iv) names of children, service organisations and any other names are designated with an initial rather than the full name – often these initials have been changed to prevent them being identified.

The findings from the participatory workshops with the children are presented under the following emergent themes:

- Theme 1: How children describe their older-headed households
- Theme 2: Children living in older-headed households work much harder than other children
- Theme 3: The relationship between children and their grandparents
- Theme 4: Difficulties children living with older caregivers face
- Theme 5: Children and grandparents see schooling as very important but poverty makes access and progress difficult
- Theme 6: Emotional stress
- Theme 7: Discussing sexuality
- Theme 8: Talking about our parents
- Theme 9: We worry about our future – fear of grandparents dying and fear of an uncertain future – forced marriages (girls)

Note that data will be presented as a whole across all seven countries and where differences emerged between countries, ages, gender or sites this will be highlighted.

Theme 1: How children describe their older-headed households

Children who participated in the research were asked to draw a detailed picture of who lived in their household. The average number of children in each household was three. The most striking characteristic is that in all of the countries most of the households were made up of at least two young children (under 12) and sometimes two older people. In all groups there were children under 10 years with a large number under three years. The families described in the drawings and quotes below are, therefore, typical.



Me, 14 years, young sisters, 6 years and 2 years, great grandmother, 92 years, grandfather 70 years, grandfathers, 75 years (ZORG)



Me, 18 years, brother, 1 year, sister, 2 years, grandmother, 85 years (UORG)

I am the only older sibling at home, my granny she's very old. My brothers are very young. (MOBR)

I am the biggest brother, another is about two years and the next is five years. My grandfather is old. (UYBR)

This is my grandmother, she is 70 years old. This is my grandfather, he is 75. This is me, I am 14. These are my two sisters; one is 12 years and the other is six years. (ZOGR)

Another theme that emerged from the drawings is that in South Africa, Tanzania and Uganda some of the younger children in the household came from different families i.e. a child of an aunt or older sister who had passed away.

This is my sister's child, she is two years, my brother, he is 10, me, I am 12 and my aunt's child, she is 11 years. This is my granny, she is 60. (UYGR)

In Zimbabwe (both rural and urban sites), Uganda, South Africa and Mozambique (urban sites) there were older brothers and sisters who worked away from home - in the Zimbabwean case most often in Zambia or South Africa.

The age of grandparents varied. About one third of the children in all seven countries lived with grandparents over the age of 75. Many of the younger children described their grandparents as "very old." They drew their grandparents with a stick and talked about how they were too old to do any work or even look after themselves.

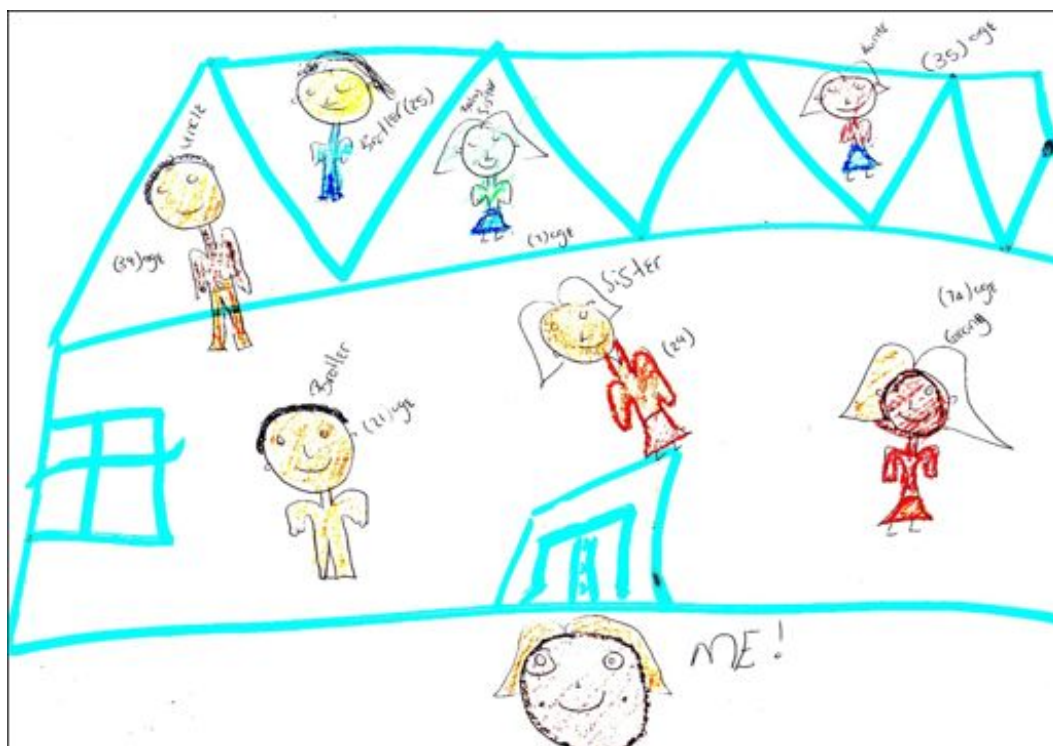


Left: My granny is very old; I have to lead her to the bath. (KORG)

Right: My granny is very old. I am the only one to wheel her (in her wheelchair). (MYRG)

Most of the children who attended the research workshops (in both the 10-13 and 14-18 age categories used for the research) were the eldest children in the house¹. The implications of the household patterns described above were felt the most by these children as they carried the burden of household work. They also did earning work and caring work for older people and usually more than one young child (see Theme 2).

Some of the South African households were the exception to this pattern. In about one third of the South African households adult members of the extended family lived in the household with the grandparent and grandchildren.



Me, 14 years, sister, 11 years, sister three years, sister, 29 years, brother, 21 years, uncle, 35 years, aunt, 35 years, granny, 70 years. (SAOUG)

¹This was not a selection requirement but it seems that participating NGOs selected the eldest child as being the one most able to talk about life in the household.

Theme 2: Children living in older-headed households have a heavy burden of work

What emerged from all children who participated in this research is that children living in older-headed households have a heavy burden of household work and they also have to work to earn money for the household. They all indicated that they worked harder than children who lived with parents or able adults.

The reasons given for their perception that they had a heavier burden of **household work** were very similar in all of the sites. There were no able-bodied adults in the house to do some of the heavier household work. Many of the children in the households were young (see Theme 1) and there was no money to give to neighbours who may have been asked to do heavy work like fetching firewood or water for money.

I'm the older sibling at home. My granny she's very old, my brothers are very young. My grandmother doesn't have the money to get anyone to help us at home. (MOBR)

Children living with grandparents work more because their parents are not present. (MYGR)

In rural households in all countries, households had small subsistence farms. In Uganda and Zimbabwe some urban households also had 'gardens' where they grew food for their needs. Children with farms and urban gardens also carried the burden of **agricultural work**. Children in these groups talked about how their families relied on the crops they grow for food so they had to work on these farms. Many also looked after livestock, even when this was outside of their gender role.

Looking after the cows is a difficult job because when there are crops on the farm they eat the crops. Then you get beaten.

Even girls look after the cows. I am looking after my grandfather's cows. People say it is the work of boys and I get upset. I have to do it because I have to support my brothers. They are too small. (EYGR)

We are digging in the field and weeding and planting vegetables. (KYRG)

Heavy household work such as gathering of firewood and washing clothes for the whole family were the forms of household work children most often said they dislike. Their main reason for disliking these activities was because they are physically demanding and time consuming. Collecting firewood was often referred to as dangerous because it involved walking long distances. In Zimbabwe, this work also involves the need to trespass on land owned by National Parks (around Victoria Falls) thus adding to the danger.

It is not allowed to collect firewood near the town so we walk 10 kilometres to find a place.

If you collect near town they catch you and beat you.

Yes you can get arrested or get punished.

I got caught once in the National Park and the rangers made me wash and clean their dishes.

You can go there late after dark so they can't catch you.

We need firewood because there is no electricity and paraffin is expensive.

Sometimes they even beat you if they catch you. (ZUYG and B)

I don't like to cut firewood and to fetch the water from far because this work is naturally for adults. It is hard work for a child. I have to do it. There is no one else. Last time I worked too much because I went by myself to gather the firewood at the field. (MYGR)

Working on the family farm, especially digging before planting, was also often listed as a task children disliked. Again, because it was physically tiring, especially in hot areas.

It is so hot and tiring the digging. You can even get sick in the sun. (ZYRG)

As Theme 1 explored, most of the children and young people who participated in the research **look after younger children**. This caring responsibility added to their burden of work. About one third of the children from all the countries talked about how they found it difficult to look after young children.

It is difficult to look after babies because they cannot be left alone. You are always worrying what they are doing.

And they get dirty all the time! (UORG and B)

But most of them also showed a high level of responsibility and real concern for the younger children in their families.

I have to work for the younger ones, they cannot do any work and we need money for food. So I do the work for them and for my grandfather. (ZOUN)

This sense of responsibility extended to the work children did to **earn money for the household**. Most of the children in all seven countries were doing some work to earn money for the household – even in the South African groups where most families received some kind of state-funded social security. The quotes below tell the story of the kind of work children do to earn money and what they do with the money they earn.

I grow enough food to eat and also to sell. We use the money for transport for granny to hospital.

I do odd jobs in the community; I wash dishes nearby and also washing clothes.

(MYRB and G)

I get money to go to the shop for my neighbour.

I wash the cars for the taxis and they pay me.

I do washing for neighbours and get money.

R: What do you use the money for?

I buy milk for breakfast.

I buy bread.

I buy food at school.

Magwinya (breakfast bun).

I wash the baby for the neighbour every day and give the money to my granny. (SAUYG and B)

In the Zimbabwean groups the work was usually in exchange for food and other basics rather than for money.

I am working for neighbours.

Me too.

And me.

R: Do you work for money?

Sometimes food.

R: Does anyone get money?

Rarely.

R: What do they pay you with?

Sugar.

Salt.

Cooking oil.

I can get US\$3 sometimes. Just enough to get Sishebo (maize meal).

I get only food.

It is ok to get food when there is none in the house but we need money for the water bills in the house. If you do not pay they close the water. (ZYUG and B)

Some of the older children had dropped out of school because of the burden of earning work (see Theme 5)

None of the children indicated that they felt resentful about doing earning work though it was often heavy and time-consuming, and took them away from school work. Most often children expressed matter-of-factly that they had little choice but to do the work to earn as this was the only way to provide for the households basic needs. They described it very much as part of the reciprocal relationship they had with their grandparents (see Theme 3).

There were a few households though where children did not feel supported and felt exploited. Most often this was mentioned in the context of grandparents abusing alcohol and wasting money that should have been used for food or school needs (see Theme 3).

Theme 3: The relationship between children and their older carers

When talking with the children about their relationships with their older caregivers what was very clear is that almost all of the children who participated in the research saw their relationship with their older caregivers as one of reciprocal care; **they were cared for by their grandparents**, but they in turn did much for their grandparents too. It seems that in many households the grandparents expressed their appreciation of the work that the children did and also did what they could to support them. This could be any household work they could manage or making sure food was cooked for the child when they returned from doing heavy earning work. Children acknowledged this support. Children took pride in being able to help their grandparents.

I like to take care of my grandmother so she can survive. She always gives me blessings. She says, 'My son I wish you all the best in what you are doing. I also wish you sell more pancakes today' (he laughs – he earns money for the household by selling pancakes in the market). (UOUB)

I love to do this (cleaning) work because it helps my grandmother and it helps to keep my house clean and prevent diseases. (MYRG)

I have a lot of duties to do. I wake up early in the morning and plough the land and then I go to school and around 2.00 I come back again and plough the land and look after the cattle. I ask help from my grandfather on how to plough the land and things. My grandfather is stressing because he says I have too much to do. He tries to give me support on the farm so I can get time for my education. (EROB)

In a group of young children in rural Ethiopia we had a discussion about the problems children faced. The quote below shows how the children empathised with their grandparent's struggle to care for them well.

R: So we are going to think about problems that you have.

Silence.

R: Any problems?

We do not have problems it is our grandparents who have problems.

Yes, they have little money to care for us because they are not working.

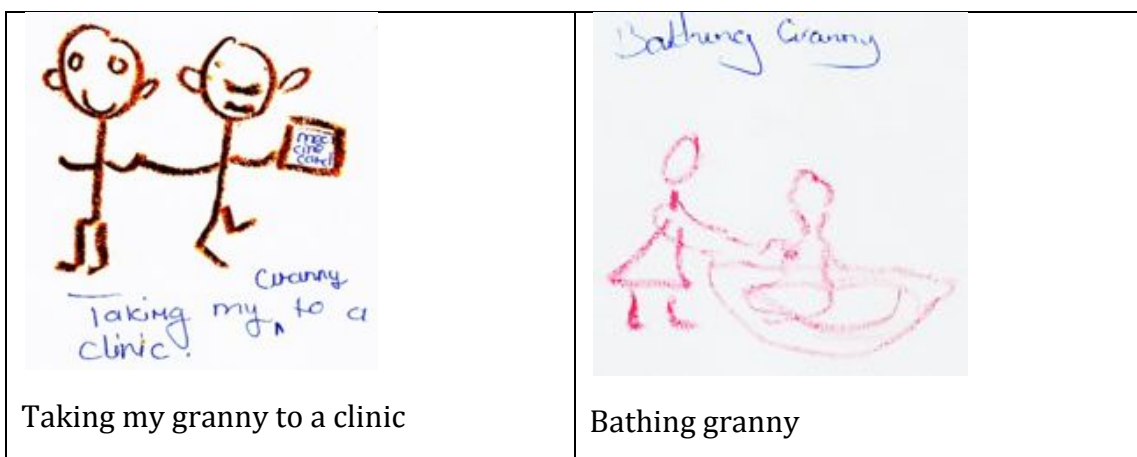
R: OK

Our grandmother has the problem of looking after too many children. She is always struggling to get things for us for school. (EYR)

Many of the young people who participated in this research lived with very old **grandparents who needed care.**

I feel bad having the granny who is always sick. Because when she is not sick we come from school and we find food ready and then we do other activities. But when she is sick we don't get food and we have to cook. When she is sick we sometimes even don't go to school. You may wake up and find she is sick. She tells you she needs porridge so instead of going to school you have to stay home and prepare porridge for her. Then you stay home until a neighbour comes and then you go to get herbs for her. (TORB)

The drawings below outline the range of caring work that young people living in skipped generation households do for the older people living in their households.





Washing granny's hair



Giving him (grandparent) medicine



Feeding my grandmother



Cutting my grandmother's nails



Washing her clothes



Cooking special food

What stood out in all of the groups was the tenderness with which children described the often intimate caring work they did for their older grandparents.

Boys and girls talked about the **difficulty of cross-gender caring**. It seems that in most cases children seek out neighbours for help in this situation but sometimes this is not possible and then it is something they find difficult.

Tasks that involved caring for grandparents were most often (apart from cooking – see Theme 4) the work that children said they liked to do. When asked why they liked to look after their grandparents they usually said it was because **they loved them**. It was clear that they took pride in looking after them.

Every day I prepare food for her, make coffee for her, support my grandmother and only then go to church or to school, because there is no one else at home to do this. I only see my friends after I have completed all the household activities – it is enough time for me to see friends because I look after my grandmother. I have to be at home. (EOBU)

I said I like to wash my granny.

R: Why?

Because I don't want to see her dirty. I like people to see I am taking care of her properly. (ZYUG)

It was clear that children **liked to live with their grandparents** in spite of the fact their households were poorer than others in the area and they had to work hard. Many of the groups talked about grandparents being better caregivers than aunts, uncles or foster parents. The perception that they would be exploited and treated differently to other children in these homes was widespread and one of the reasons why they feared the deaths of their grandparents (see Theme 9).

During one of the activities we explored **conflict between children and older caregivers**. The main cause of conflict in all of the countries was work. Children in Tanzania, Uganda and Zimbabwe talked about how collecting water and wood often led to conflict between them and their grandparents. This is because it was a communal activity and it gave them a rare chance to socialise with other children and their grandmother often got angry because they dawdled and played on the way home.

If you are late in coming from fetching water because you play with your friends on the way then your grandmother beats you. (TYRG)

In the Tanzanian and Ugandan older groups children described how their grandparents sometimes mentioned their parents when they became angry.

My granny shouts at me. She says my mother died and I will also die. (TORG)

Children in the South African groups said that washing the dishes for the large extended family they lived with often fell to them and that this was time-consuming and hard work. They talked about resenting the fact that they were left to do this work alone and this resentment often led to conflict between them

and their grandparents, and other older members of their household.

Sometimes after supper you have to wash all the dishes and there are many it can take one hour. You wash some and they bring some more! It's also big pots. Then you do homework late. The others in the house are sitting and drinking tea and I am washing. I end up doing the washing badly or I end up shouting at them to stop and to help me.

Sometimes I pretend I am sick. (SAOUG)

A few children in groups in Tanzania, South Africa and Zimbabwe talked about the fact that their older caregivers abused alcohol and that sometimes this made them rude, angry and even abusive.

Always we feel very bad when our granny is drinking alcohol and she comes home and she asks whether the food is ready and if the food is not ready even though we were doing other work she doesn't recognise this she just starts fighting. (TROG)

Our grandmother is drinking and abusing us and using vulgar language. (KROG)

When we talked about **discipline** it was clear that in a few cases grandparents punished children harshly. Most of the children said that their grandparents disciplined them by beating, especially if they did not do their work at home. They also talked about how older carers often shouted at them and how they wished they would not do this – they wanted them to talk and explain what they had done wrong.

Then your gran sends you to collect firewood and you go instead to play football and if you are sent somewhere and you are late in coming back. If you are late in coming from fetching water then your granny beats you. (TRYG)

Some days they are not bad but other days they often hit when we fight with each other. (MRYB)

Eish! It gets out of hand (the shouting).

When they shout at you and you respond back they say, 'now you are responding, you have to be quiet!'

They shout when you do not do something in such a hurry. But sometimes you are doing homework. I wish they would just talk quietly. (SAOG and B)

There were households though where the older caregiver talked to children rather than beating or shouting at them. Another disciplinary strategy that children described was older carers bringing in neighbours and family members to talk to the child when they misbehaved.

They call a meeting with the rest of the family. (SAUOB)

My grandmother calls our neighbour to come and help when my little brother is too naughty. (URYG)

One issue that came up in one of the South African groups where a few of the young people were HIV-positive was their feeling angry because their grandmothers did not always keep their status confidential.

Like my grandmother she did something, she went to buy some pills to boost my immune system. I asked her did you tell them I was HIV-positive – maybe I cannot take these pills and she said yes. It was hard because I don't want anyone to know. (SAOUG)

In the Mozambican and South African groups it was also clear that some of the children felt their grandparents did not understand their lives and they felt they overprotected them. This came up in relation to the radio, mobile phones, television and being friends with boys.

When my grandpa shouts that the radio is too loud I just walk away.

And they shout about Mxit (a free mobile phone-based instant messaging system used by young people to chat to friends).

And they shout especially about boys and this soapie that comes on TV, 'Intersections' they say, you are not allowed to watch this...

Even with boyfriends – I have to learn what is responsible and irresponsible for myself. They should realise we are teenagers. If they keep babysitting me, when am I going to learn.

They must see that it is not the old ages any more. Like they say 'in my time we had boyfriends only at 21 but nowadays you get a boyfriend at 14.

For instance I came home with two boys from the support group and my granny said, 'look she is bringing men into the house'. When I tried to explain it was hard to explain that these boys are just in my support group. (SAUOG and B)

Children in all of the groups felt that one of the important roles their older carers played was to **teach them about their culture and how to behave properly**. They often talked about older carers telling stories and how much they appreciate these. These stories were sometimes about times past, often about how to behave and, in a few cases, about their parents (see Theme 8). It was clear that children enjoyed these teaching times and valued the advice they were given.

Theme 4: Difficulties children living with older caregivers face

Inadequate shelter was a difficulty mentioned by most of the children. In the drawing of their household, children were asked to indicate the nature of their dwelling. It was clear that most of the dwellings were inadequate. In many cases this was identified by children as one of the biggest problems in their lives.

The house is broken and I cannot get money for repair.

We are always sad because the rain is coming in the house. (TYRG and B)

Our grandmother's house is very small so we have to sleep in the small outside kitchen. (KOB)

Unproductive farms were another difficulty mentioned by children. Children were asked to indicate any farmland they had around the household in their drawings. In rural households in all countries, households had small subsistence farms. In Uganda and Zimbabwe some urban households also had 'gardens' where they grew food for the households needs.

What emerged in all of the groups where households had farms was that these farms were not productive. Children in all of the groups linked the unproductive nature of their farms directly to their status as a skipped generation household. The unproductive nature of the farms meant that the households represented in this study were not able to provide basic food needs from their farms or to sell excess produce to get money for school and other needs.

Children living with granny mostly eat from the shamba (small household farm). If they are planting and they are waiting for the harvest they just starve because they have no food.

That is true about the hardship. In the one house (where children live with a grandmother) there is not enough food because the mother is dead and the father is missing. And worse still he sold all the shambas and just left a small piece of shamba with the granny. So they sometimes have to work but it is just children working.

Sometimes in these houses you will see they cut the bananas before they are ripe to eat because they are so hungry. (TORB and G)

The drawing of the household also allowed us to explore who brought in an **income**. In South Africa all of the households accessed grants. These were old-age pensions for grandparents and child-support grants for children under 18. In about half of the families in the South African group these were the only sources of income. In the other 50% of households older brothers or sisters, or aunts and uncles, worked and contributed extra money.

My granny is getting pension and my sister is working. My sister is working late shift at Spar (supermarket). (SAOUG)

R: Who brings money into your house?

My little brother Kagiso.

R: Oh, is he earning money?

He gets a grant. (SAOUG)

In the other six countries represented in this research most of the families had no adults who brought money into the household.

R: Who brings money into the house?

No one, my granny is too old and my father has passed away. (UYUG)

I look after all of them. I do some odd jobs to earn a little money like selling bananas. (MYRB)

In Kenya, Uganda and Zimbabwe a few of the children talked about household members such as older brothers, uncles and aunts who lived in a large city and sent some money home. In the case of Zimbabwe many of these family members lived in South Africa or Zambia.

My two brothers are working in Kampala. Some months they send money to us for food. (UYRG)

My older sister goes across the border (to Zambia) and she sells vegetables there for a man who pays her. She brings us money when she can. (ZYRG)

Most often it was the older children living in the household who did informal work to earn money. Some older children had given up school to work to earn money but many more worked for neighbours after school and at weekends (See Theme 2).

One of the research activities involved children and young people drawing all the activities they did in a day and then identifying the problems they faced in the day. Discussion centred around which of these problems was the most serious. In all countries the problem most often mentioned as the biggest was the lack of basic needs. Children mentioned food, lack of soap, clothes and blankets and the means to repair houses. . A lack of food was the problem mentioned most often.

I put 'no food' as a problem.

R: How big is the problem?

Very big.

For me too.

And me.

And me.

We don't have food because of a lack of money in our house.

Sometimes we only have one meal a day.

Yes, when we come back from school we eat. That is all.

And it is not enough. We are not full.

R: What do you eat?

Yams, cassava.

Posho (maize meal).

With dry tea and some sugar.

No sausages! (laughter)

R: What about beans?

Silence.

Sometimes we get beans.

R: Do the other children living in your area have the same problem?

Some, but it is worse for children with grandparents.

Because they are not working.

They are old! (UYRG and B)

One observation children indicated during the activity about household work was the activity they liked the most being cooking. When asked why they said cooking, they explained that it meant there was food available.

R: Why did some people say they liked to cook? Why do you like to do that?

Because if you cook it means there is food. (laughter from the group).

Yes, you do not cook if there is no food.

We become happy when there is food to cook. (Zoug and B)

In the groups run in Ethiopia, Mozambique, Tanzania and Uganda, children also mentioned a lack of food in the context of school. They talked about how difficult it was to concentrate at school when they were hungry (see Theme 5).

In South Africa it seemed that a lack of food was a problem when the social grant

money ran out. It was not only food that was an issue when the grant money was finished, soap was also a problem. The day that grants were paid out were a highlight for all of the children as their grandmothers often gave them a treat on this day.

Sometimes at the end of the month we run out of money and there is no food to take to school. (SAYUG)

A lack of soap at all times was a problem mentioned in all of the other research sites. Clothes were another basic that children did not have. Note how the children in the quotes below point out that having clean and respectable clothes was linked to acceptance in the community and to self-esteem issues.

In a single desk we sit two, now it happens that one goes to the classroom with that old uniform, they make groups in the classroom and they start discussing about you. What kind of a student stayed for a long time at her place – Friday to Monday and she couldn't even manage to wash the school uniform but you sit on your own and you know the real situation – that you could not get soap to wash the clothes, in fact there is no soap. (TROB)

Children talked about how the lack of basic needs affected the relationships they have with their grandparents. Children in the Tanzanian groups talked about how difficult it is to continue working hard when there is no food in the house.

If there is no food you just murmur (quietly complain). You put wrinkles on your face like this (she shows a cross face). You go and do the work but you just complain and murmur. (TRYG)

The South African children talked about how much they loved pension day because their grandmothers sometimes bought them a treat. Some of the Tanzanian children who participated were part of a project where grandparents received a pension. They spoke about the treat on pension day.

On pension day and when Gogo (granny) gets the grant she buys for us a chicken and even Danone (fruit yoghurt). Then we are all happy. I love the day for grants. (SAYUB)

What is interesting about this is the small gifts clearly build the relationship between children and their grandparents as the children perceive them as expressions of love.

We always help our grannies but we come to help them more when they bring us a gift because you feel you have hope and you are happy. (TYRG)

I like to stay with my granny. Sometimes she gets cross but when Christmas comes near she buys me a present and then I really love her. (TYRB)

A lack of money for health needs was another difficulty children mentioned.

One of the big problems is no money when we are sick. My grandfather goes and begs from anywhere when I am sick and also when granny is sick. (ERYB)

Discrimination from peers and adult community members was another problem children mentioned often. Usually this discrimination was related to poverty but children also described discrimination related to the fact that they lived with and took care of an older person.

The rich kids laugh at you if you don't have lunch and you eat at the feeding scheme. (SAUOG)

They ask you, 'where is your mother and father? Why do you live with your granny?'

Sometimes they say you like tea (you are old fashioned).

Questions like, 'where is your mother?'

Then you feel bad. (SAUYG and B)

When they see me with my grandmother they shout, 'you will never get married because you are looking after that old lady'. That makes me to feel very bad. (UROG)

The say we take advantage of our gogo (granny)

They say children who live with a granny are spoilt because they say gogo will let the children do as they want. They are so tired of running after these kids.

This makes you to feel hurt.

Sometimes this is true though – they do eat (steal) gogo's money – the gogo's are so old they do not see. (referring to the old-age pension) (SAUOG)

In the Kenyan group children mentioned that people often said that they had AIDS because their parents had died from it.

Theme 5: Children and grandparents see schooling as very important but poverty makes access and progress difficult

The Mozambican group mentioned that some grandparents only send children to school during exam time but on the whole it seems that most older carers encourage school-going.

My grandfather also says I must go to school. It is very important.

My grandmother too, she says my future lies in education so we have to attend regularly because she says, 'If I die your future will be good'. (EROB and G)

I have never seen my granny stopping me from going to school and though she has never been to school she always regrets that my father did not take me sooner to school. Sometimes I even tell her I have a headache and she feels I am cheating and she says go to school first, ask for permission and then come back. (TORB)

But the children reported many difficulties related to accessing schooling. Mostly these related to the lack of money in the household for fees, school materials, uniforms and other things demanded by the school, such as toilet paper or building fees. Children in all of the groups (except the South African groups) described being beaten, turned away from school or sent home from school because they did not have funds. Sometimes this involved missing many days of school.

They are beating me at school.

R: Why?

Because I have no books.

R: Did anyone else get beaten at school?

Me. Because I did not have toilet paper.

And me.

And me.

When they say you must bring toilet paper at school and you do not the teachers get very angry and they beat you. But my grandmother has no money for toilet paper. (URYG and B)

If the teachers at school have sent them back home because of no shoes and socks so they will just stay at home until they get shoes and socks. Because I had no shoes I stayed at home for a month before my granny had money to buy me shoes. So after the month my granny could have money and she bought me plastic shoes. (TRYB)

It was also clear the stress of missing school and finding ways to 'dodge' the teacher who had sent them home for one reason or another after a few days added to their emotional stress.

I just stay home from school for a few days and then I think she (the teacher) will forget so I go back and I dodge her. I just try to go to class and dodge her. (UROB)

Some of the older children in every older group had dropped out of school because the burden of earning and caring work had become too much. This was a cause of great emotional stress to them.

I stopped to go to school because I had to do work for money for the house. I am selling. There was no money for exams and for school so I had to drop (out). (ZUOB)

But not only access to school was a problem, progress was another issue. The children in all the groups talked about how the stress of their home situation affected their progress at school. Sometimes the stress was related to hunger, sometimes to being sad, sometimes to discrimination from other children at school and in some cases teachers.

Sometimes you are sitting at school just thinking about your mother and you are doing bad because you are thinking too much.

You even remember the past and even if you study hard you can't do anything in exams. Worry is why children fail. (TORB)

Children in all seven countries said they were often late for school because they had to do essential household chores or work in the fields before they left for school in the morning.

If you help your grandmother with washing utensils and the other work in the house then you become late and they (the teachers) beat you. (UYGU)

I am late because of house chores, cleaning the house, fetching water and cooking food for grandmother and then going to school. (MOGU)

I'm delayed because first I go to the field and when I get back from the field I prepare and arrive late at school. (MYBR)

Children in almost all of the older groups talked about how difficult it was to find time to do homework because of the myriad tasks they had to do at home.

Theme 6: Emotional stress

Emotional stress was obvious in most of the groups. The most common signs of emotional stress described by children were sleeplessness, bad dreams and isolating themselves - these were mentioned by some children in every group.

I sometimes cannot sleep at night. I lie and think about my mother.

And bad dreams – sometimes I am seeing my father in his grave. (UUOG and B)

In all of the groups children most often described the cause of emotional stress as their sadness at the lack of parents.

There is always a space in you that always misses your mother. And when girls at school say 'my mother is going to do this for me.' And then you feel sad. Especially on mother's day you do miss your mother. (SAUOG)

It was clear that this sadness was exacerbated by the poverty they lived in. Children described thinking often that if their parents were alive they would not be in the difficult position they were in. One or two of the younger children in the South African and Ugandan groups also talked about how they sometimes felt angry that their parents had left them with their grandparents and had no means of economic support.

I think that my father and mother should not have died. If they were still alive I would not be living here but they would be looking after me. Then I am feeling very angry. (ERYG)

Emotional stress was made worse by the teasing they received from other children which was related most often to their economic circumstances, but also sometimes to the fact that they lived with and looked after older people (see Theme 4).

Children mentioned that playing with friends at school and around the neighbourhood, listening to the radio and going to church were important ways for them to relieve stress. About three or four children in each group mentioned that they talked to their grandparents when they felt sad. One young child in Ethiopia said she always felt better when there was food to eat.

Theme 7: Discussing sexuality

There was evidence of some homes where grandparents were open about sexuality. Girls in one South African group described how their grannies had talked to them about their changing bodies and about the need to protect themselves from HIV by having only one partner. Two older girls in the Ugandan rural group also talked about how their grandparents discussed relationships with them.

For me my relationship with my granny is tight. We are very close which means we talk about anything, whatever difficulties I face in life. We talk and she supports me. (SAUOG)

My grandmother always talks to me. We sit and talk about school and she advises me about my life. I talk to her about my friends and she says I must always look for good friends. We talk about HIV and how you can protect yourself. (UROG)

Boys did not mention having these discussions with their grandparents. Grandfathers seemed to discuss work and school most often and most grandmothers did not have discussions with boys about issues of sexuality. Apart from those few who clearly had open discussions it seems that young people's perception of the way their older carers teach them about sexuality is that it involves admonishing them NOT to do certain things.

Yes she talks to me she said that I have to study and not play on the street because I will get AIDS and die. She says it is good to study and get a good husband.

My grandmother barely speaks. She just tells me to not play with men or I will catch a disease. She says I must study to be a teacher, nurse, police when I grow up. (MROG)

It was clear that this was often done with a positive aim on the part of the elders but young people said they wished they could discuss issues like girlfriends and boyfriends more openly with their grandparents.

And you know some grannies don't understand like a mother. They don't see that the child is a teenager and going through some difficulties. Grandmothers are overprotective and it is hard for you to speak to them about issues, for example, about boyfriends and stuff. If you do talk they will just shout, 'You are dating!!' But your younger mother would understand – she would remember being a teenager and say 'I did that stuff but you need to be careful'. But grandmothers ...eish! (SAOUG)

In South Africa, Tanzania and Uganda children talked about how they wished their grandparents would talk about relationships between boys and girls openly.

I would like to talk with her about boyfriends because that's the problems we are facing and dating things. But if you try to talk about sex and things they say you are just interested in boys. (SAUOG)

My grandfather does not talk about life. He tells me about my school work to do it well but he does not talk about my life. I would like to talk with him about who I should marry when I am grown. (UUOB)

Some of the children in South Africa, Uganda and Zimbabwe said their older carers linked protection against HIV to the children's dead parents, admonishing them not to live the way their parents had done and then they would be safe. It was clear that in a few cases this was done in a resentful way.

My grandmother says that I am like my mother, I play with boys and I will die like my mother. (ZROG)

Theme 8: Talking about our parents

One of the issues all of the children wished they could discuss more openly with their older carers is their parents. Most of the groups said that older carers seldom spoke about their children's' deceased parents. They wished that they would tell them stories about their parents when they were alive and talk about

their parents' deaths. Mozambican children described how they enjoyed it when their grandmothers told them stories about their parents.

She tells me about my father. She said my father used to travel a lot to Maputo and he was a bricklayer – he built houses. (MRYG)

Children in many of the groups (even in some of the younger groups) did acknowledge though that it was hard for their grandparents to talk about their children as this made them very sad. Because of this, in spite of their wish that more was said children did not raise the issue with their grandparents.

I know it is hard for her to talk. I do not feel I can ask her about my mother, she becomes so sad so I do not talk about her. (ZUOG)

Theme 9: Grandchildren worry about their future

Apart from worrying about basic needs in the household the most often mentioned worry for the children was the fear of their grandparents dying. One young girl in Uganda described how she got up every morning and checked on her granny because she worried she may have died in the night.

I get up and then I go to check on my Jaja (granny). I check that she is still there.

R: Where could she have gone?

I think maybe she has died in the night. So every morning I check her. She is very old. (UUYG)

The fear was related to loss of someone they loved (something all of them had experienced before) but also to the fear of what would happen to them when their older carer died. Children in Ethiopia, Mozambique, Tanzania, Uganda and Zimbabwe were afraid of being sent to live with distant relatives or foster parents because they knew many children who were exploited and not loved by these carers.

Our granny is always our hope so we think one day if our granny is not around we shall be in trouble. Because our grannies always treat us like their own children because they know we are the children of their children. So they treat us even better than the uncles and aunts can do. You think that if your granny dies you will go to stay with your uncle and the wife of your uncle may be treating you unfair and may be treating you worse than she treats her own children. (TYRG)

Girls in two of the Ugandan groups and one of the Ethiopian groups talked about the fear that they would be forced into marriage and made to give up school when their grandparents died as this would be one way of them being taken care of.

They can make you marry if your grandmother dies.

R: Who is they?

The uncles.

They do not want to look after you.

R: Is anyone else worried about that?

Me.

And me. (EROG)

5. Comparison, synthesis and summary of findings from children, older carers and literature review

There is remarkable congruence between the findings of the literature review, and older carers and the children from their households have to say about the positive aspects of relationships between them and about the issues that cause stress in the household.

Lack of basic needs

The literature review highlights basic needs as the main issue faced by older-headed households. Children describe how they struggle with a lack of everyday needs, they don't have soap to wash or food to eat, and their houses are often broken and leaking. Older carers tell us that the biggest problem they face is providing basic needs such as food and clothes. Both describe how this places stress on the relationship between carers and children, and often causes conflict in the household.

Agricultural capacity

Children spend a lot of time working in the fields or looking after animals, but they acknowledge that this is not enough to make the household self-sustaining. Older people worry about the lack of agricultural productivity of their households. The literature review also highlights heavy labour on farm land as an issue faced by children.

Lack of physical capacity to do household work or earn money

Children describe how they have to do household work beyond their capacity because there are no able-bodied adults in their homes. Many also carry a heavy burden of earning money. Older carers talk about the physical and mental weakness that comes with age and how this places an extra burden on the children. The review of research also brings attention to the incapacity that comes with age and how this challenge is felt in older-headed households.

Parenting skills

Children describe how their grandparents do not always manage to resolve conflict in the household or discipline wisely. The research and literature review show how this often relates to the need children have for recreation with friends. Older carers worry about their lack of parenting skills.

Mutual support

Children talk about the love and support they get from their grandparents and how much they value this. They also describe how they willingly look after the older people in their households. Older carers see one of their roles as the

provision of love and support and they willingly supply this. This issue does not appear in the literature review. Very few research studies have included talking directly to children and has therefore missed this important insight of mutual support.

Lack of social support

Children describe how they are discriminated against in the community because of their poverty and being raised by an older carer. Children living in older-headed households are often isolated without social support. Older carers describe how family often turns against them and how little support they get from community members. The review of literature shows how this lack of support extends beyond the community to the lack of support from government-level structures and even NGOs which often neglect to even mention older carer households in policy and programme documents.

Emotional stress

The research literature highlights the issue of grief and fear among children and older people. Children describe how they grieve for their parents, worry about their grandparents dying and about what they will do when this happens. Older carers feel their own grief at the loss of their children and worry too about their grandchildren's future. They also talk about their lack of skill in dealing with the grief the children feel for the loss of their parents.

Talking about sexuality issues

Research tells us that older people do talk about sexuality issues and often do this within a traditional context, but that much of what they teach is admonitory. Children describe how grandparents talk about sexuality in the context of the things they must not do. They wish their older carers would be more open to discussion and questions about sexuality. Older carers attempt to teach children about sexuality with the resources they have and know about. They tell stories and teach traditional values of instilling respect for others and living responsibly, but are also frank in discussing the consequences of risky sexual behaviour. They admit that they struggle with helping teenagers.

Communication

The literature review and research with children and their carers points to the need for education on parenting and communication skills. This would enable older carers to motivate the children to talk about their feelings and participate more fully in the management of household life.

Conflict and discipline

A main cause of conflict, according to the children, was work as they felt that their grandparents did not appreciate that they needed time to socialise with other children. A reason stated from the literature review was older caregivers

would prefer to raising children in the same way they raised their immediate children, that is, with strict, authoritative rules and without taking generational differences into consideration.

However, older carers were aware that the orphan children they cared for needed more care and attention since they were sensitive as a result of their situation. Another source of potential conflict was the fact that some of their older caregivers abused alcohol which could make them rude and even abusive. Corporal punishment in relation to discipline was mentioned by older carers, with children also stating that grandparents punished children harshly. Children wanted their carers to talk and explain what they had done wrong. Some older carers also mentioned that discussion, tolerance and being supportive were approaches which they used. Older carers felt that older children were particularly difficult to handle. Some older children were in agreement about this saying that they often got angry with their grandparents because they did not understand their lives and were overprotective.

Disclosure

Children wished they could discuss more openly with their older carers about their parents, but claimed that older carers seldom spoke about them. The children acknowledged that it was hard and stressful for their grandparents to talk about their own children, thus, they seldom raised the issue. The literature review cited the grief and trauma which older caregivers experience due to having lost one or more adult child to HIV and AIDS. Older carers spoke of how difficult it was to disclose the cause of death of their own children. They knew it was important but said it would not lessen the grief of the child and they worried about the discrimination the child might experience if they disclosed the cause of their parent's death to outsiders. A few older carers claimed they revealed the cause of death when they felt that the child would not be psychologically affected.

Education

Children see education as very important for their future yet the poverty of their households' results in them missing school and often dropping out because they do not have money for fees and other related costs. Older carers have a commitment to education but sometimes practical needs such as agricultural work or caring work means that children have to miss school. Worry about fees and school materials causes stress for older carers. The literature points to the fact that older people do not always have a commitment to schooling, however, this was not evident in this research. It's possible this is because our research work uses a participatory approach that allowed us to see the household from the children's as well as the older carer's point of view and thus gives us a more nuanced understanding than that given by the largely quantitative studies referenced in the literature review.

Health care

The literature review highlights the difficulty of accessing health care as an issue. Older carers raise this too, especially their worry about the health of young HIV-positive children in their care. Children talk about it in the context of lack of money for medicines and the extra burden that caring for their older carer's health and the health of young children places on them. They have to earn money for medicines and transport to the clinic and spend time looking after ill people in the household.

Documentation

One issue raised by the literature review is that research seems to suggest that older carers do not understand the importance of birth registration and other documentation as a protective mechanism for the children in their care. There was some evidence from the children's workshops that some children understood the importance of documentation. Children mentioned the cost of transport to centres where documents could be accessed. Children and older carers did, however, mention how important wills were and how they would appreciate help with these. This issue was most often mentioned by children and the older people in the context of their fear for the future.

6. Recommendations

The literature review, the findings from the older carers and from the children point to a number of issues that need to be addressed to support households headed by older carers.

Older-headed households as a positive form of care for children

- The relationship between children and older people has been shown in this study to be largely reciprocal. It is important to remember that children provide a supportive and protective role for the older people in these households. Children who live with grandparents are happy, on the whole, with the relationships they have in the household. They prefer to live with grandparents than with other relatives or foster families. The findings of this research point to the fact that every effort should be made to support intergenerational households as a positive alternative form of care for children who are orphaned and for the older people themselves. This requires embracing a family-centred, integrated approach to the challenges and needs of children and older carers affected by AIDS.

Focus on the rights of older caregivers and the children in their households at national, regional and local level

- This research shows that the right of older caregivers and the children in their households to basic needs is violated. Human rights frameworks at the global, regional and national level need to build in indicators which directly address the rights of older-headed households. Rights-based indicators that relate to older-headed households should also be built into revised UNGASS indicators and the M&E frameworks for regional and national minimum package of services and psychosocial support for children.
- Regional and national policies, strategies and programmes across the sectors (HIV and AIDS, Children, Social development, Education and Agriculture) should be reviewed by policy makers in order to address the specific needs of older carers and children. Regional and national plans of action need to include programmes which provide relevant and appropriate support to older-headed households affected by the impact of HIV and AIDS.
- Lack of inheritance rights, or the lack of implementation of relevant legislation, place households headed by older people at risk. Review of legislation around inheritance and advocacy to implement it where it exists should be priorities. Paralegal advice and other legal services, including will writing, should be part of any programme working with older headed households.

- Children who come from older-headed households are discriminated against at school. Schools often require provisions beyond the capacity of the households. Advocacy at and within the school system needs to emphasise the need to adapt requirements for children who come from very poor households.
- Children and older people who live in older-headed households struggle to access health care. Finding money for medicines places an extra burden on them. Advocacy at policy level needs to focus on helping older-headed households' access health care more easily.
- Children living in older-headed households do work that violates many of their rights. Alongside supporting these households through social security (so that the children do not need to work) advocacy needs to focus on educating communities about the danger of inappropriate work for the growth and health development of children.

Programmatic support for older-headed households

- Civil society organisations (CSO) have a major role to play in supporting older carers and children. CSOs should review their strategies and programmes to reflect a family-centred and caregiver approach to reach older carers and children.
- Households headed by older carers have reduced agricultural capacity and cannot be self-sustaining because there is reduced labour. Programmes to support the agricultural capacity and livelihoods of older-headed households need to be implemented. These need to be tailored to the reality of families that have little physical capacity.
- Intergenerational relationships in older-headed households are negatively affected by the deep poverty that many of the households find themselves in. Social protection measures including social transfers need to be put in place to support households headed by older people - this will contribute not only to the physical wellbeing of children and the older people who care for them but also to their emotional wellbeing.
- Older carers face significant emotional stress because of their own grief and because of the responsibilities forced on them by the loss of their own children. This research points to the value older carers place on support groups for them where they exist. Psychosocial support targeted at older carers needs to be put into place to help them cope with the demands of parenting and the responsibilities they face. Local support groups are an important way of doing this.
- Children living in older-headed households experience significant emotional stress. This is caused by grief over the loss of their parents which has not been dealt with, the poverty they experience and the extra

work they have to do. They also worry about their future. Psychosocial support targeted specifically at the emotional needs of children living in these households needs to be provided.

- Older carers face challenges related to communicating with and raising children and teenagers, as well as challenges they did not face when they had to bring up their own children, such as helping to protect the children from HIV and AIDS. Older carers need education and support in parenting and communication skills.

Participation of older people and children

- This research shows that older carers and children have insights into their lives and circumstances that would enable more effective legislative and programme intervention. They should be involved in designing, implementing and monitoring programmes that concern them. Formal structures and systems should be created for meaningful older caregiver and child participation at national, district and community levels.

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