

child CARERS

**Child-led
research with
children who
are carers**

**Four case studies;
Angola, Nigeria,
Uganda and
Zimbabwe**



Save the Children

Acronyms

AIDS	Acquired immune deficiency syndrome
ESRC	Economic and Social Research Council/s
HIV	Human immunodeficiency virus
NGO's	Non-Government Organization
OVC	Orphans and Vulnerable Children
RIATT	Regional Inter-Agency Task Team
UK	United Kingdom



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Contents

Executive Summary	1
Child-carers in Angola Nigeria, Uganda and Zimbabwe	3
Child-led research	7
Findings	12
Recommendations for policy and programming	23



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Executive

Summary

This is the summary report on the research phase of a project looking at the needs of child-carers in four African countries; Nigeria, Uganda, Angola and Zimbabwe. The research consisted of a literature review and participatory child-led research in one site in each of the four countries.

The research used an innovative child-led approach. In each site children who were carers of sick or disabled adults, elderly grandparents or young children came together for a workshop. At this workshop through a number of participatory activities they shared the stories of their lives as carers. They also learned how to use a camera and recorder and how to conduct an interview. Using their own research questions they then went back home and interviewed and photographed child-carers known to them. The information they collected was recorded in a second workshop. This child-gathered data was then written up into a case study of the life of child carers in that particular area. The child-led approach resulted in the collection of rich and detailed information with insights that could not have been gathered by adult researchers. A total of 124 children (61 girls and 63 boys) aged between 8 and 17 years participated across the four case study sites.

The findings of the research show that the children have a number of inner resources. They have a strong sense of responsibility, they are able to seek out help from the few sympathetic adults they know, they are able to problem-solve in order to make a living out of various tasks, and they could solve problems among the children at home. They also showed maturity and emotional strength in the way they parented younger children.

Many of the children also had a positive and supportive relationship with those they cared for. A few of them also had support from friends and other child-carers they knew.

But for most of them the other resources that promote resilience were largely absent. They had no help in accessing their everyday needs and carried the heavy burden of working to earn money and find food. They

had little support from adults or other children in their community. They did not have easy access to health facilities or to information that would have helped them with their caring responsibilities. They were deeply committed to going to school, but the institution itself placed many insurmountable - as well as unnecessary and/or incomprehensible - barriers in their way.

Various risk factors were also present in their lives. The heavy work they had to do placed them at risk both physically and emotionally. The discrimination they experienced, particularly that directed at their gender identity, affected their self-esteem. They showed signs of emotional stress, for example many struggled to sleep at night and others had nightmares. Much of this stress seemed to be related to grief that they could not deal with in the face of the multiple deaths they had experienced. They often felt as if their responsibilities were overwhelming.

They had no access to accurate information to protect them, or information about the illnesses their parents had and the likely outcome. They had little institutional support in their caring responsibilities. The peer-support they had was informal and created by them. They had few adult role models or mentors.

It is this lack of outside resources to support child carers that should be the focus of advocacy. Advocacy needs to take place at a regional level – through initiatives such as the Regional Inter-Agency Task Team on children and HIV (RIATT), and at a country level – with national, district and community government and with local NGOs. Messages need to include ensuring that child carers have adequate psychosocial support; access to information on care giving and HIV and AIDS as well as access to grants, cash transfers and education. 🌱



"This is our house. I am the one looking after it. My mother is sick."

(Girl, 9, Zimbabwe)



Natalie's house.

"This is the photo I took of Natalie's house. Her grandmother is in the picture, she is taking porridge with the smallest child. The grandmother and small child are both sick. There are nine children in the house altogether. They are all very young. Natalie looks after them all. She is 16."

(Child-researcher
of 16)



Child-carers in Angola, Nigeria, Uganda and Zimbabwe - a summary of existing research¹

The children whose roles and lives are the focus of this review share many experiences related to poverty and the presence of HIV/AIDS with the vast majority of children in their neighbourhood and country. However, the literature points consistently to certain key distinctions that relate firstly to the nature or quality of the care role they perform, and secondly to the magnitude of that role.

Evidence points to children in this region assuming a dominant role as caregivers in the following circumstances:

- Living with HIV-infected parents, who have chronic and debilitating illness, and may be approaching death.
- Living with and caring for increasingly frail grandparents, who may have formerly been caring for the child.
- Heading households and caring for younger siblings, usually as older children or young adults.

The precise scale of 'child-caring' remains unknown, but is likely to be widespread and unevenly distributed. Children are more likely to be caring in regions where HIV rates have been high for several years and are continuing to climb, local sources of income are few (prompting healthy adults and children to migrate for work), proportions of single-headed households are high, health and social services are minimal (including Anti-Retroviral-Therapy access), and communities are, by default or design, relied upon to provide 'home-based care' to sick members.

The data suggest that children as young as eight years take on the care of sick adults and siblings, and that these roles can continue for several years, perhaps for a series of sick or frail adults. Too little is known about the psychological impacts of emotional care and the assumption of responsibility, or 'parentification', by young children in African contexts. Older children, whose caring roles undermine their school attainment, recognise this long-term cost to their well-being.

Girls appear to have primary care responsibilities for siblings or sick/frail adults more frequently than boys. But gender divisions of labour are highly sensitive to socio-cultural preferences – for example, for gender-matching in caring – and the sheer scarcity of human resources. This means that the growing proportion of boys who are full-time carers can be overlooked within local neighbourhoods and policy provision.

¹ Bray, R (2009). *A literature review on child-carers in Angola, Nigeria, Uganda and Zimbabwe*. Save the Children UK: Pretoria.
This is a summary of the fully referenced literature review

Close scrutiny of research investigating care dynamics within families and neighbourhoods reveals the following:

- Children are performing a physically, mentally and emotionally demanding set of tasks during a period in which their own lives are undergoing profound change.
- The experiences and implications of living with a parent or other close relative with acute, debilitating illness, as well as those of bereavement and grief, need to be integrated into our analysis of 'care'.
- We should not assume a linear relationship between AIDS sickness in the home, children's care roles, orphanhood and further care roles for children.
- For children and adults, caring is a two-way relationship, even when aspects of the care role have been reversed. Unwell adults who are being cared for by children continue to try to care for these children in significant ways. Greater understanding of the roles of 'child' and 'parent' is required, in order for insight to be gained into the way in which reciprocal caring can bolster resilience.
- The quality of the relationship between child and parent-figure is the most effective predictor of child mental health. Factors that can improve adult quality of life – for example, Anti-Retroviral-Therapy, health care and reliable income – raise the standards of adult care of children, improve the quality of their relationship and thereby have important indirect benefits to child well-being.
- Children are likely to assume caring responsibilities at the point when a household is in severe economic decline and has little or no human capital with which to engage reciprocally in social networks. Adult sickness may attract stigma related to AIDS, or to the inability of the household to contribute to social networks. Social isolation puts immense strain on the child–adult relationship, and poses a risk to livelihood because food and other basic goods are not shared.
- Child-carers often manage to stay in school, but their attainment suffers owing to sporadic attendance, exhaustion and failure to complete tasks. Policies that focus only on improving enrolment among orphans and vulnerable children will not address this problem.
- The caring role may strengthen children psychologically and socially in ways not available to those who witness debilitating illness in the home while others perform care. The younger siblings of child-carers may be highly vulnerable in this regard, especially in the context of likely future bereavement, relocation to a relative or remaining with an older sibling whose ability to care is compromised.

Factors that build resilience in children who care, as well as in those who live with sick relatives or are orphaned, are:

- the quality of the relationship between child and adult as an end in itself and as a mediator of children's inclusion in social networks;
- the provision of health care or social grants;
- the capacity of social networks to provide food, sustain livelihood and ensure that children and adults are included in the community.

Striking parallels in the mechanisms undermining well-being for children in the above scenarios include:

- economic impoverishment due to difficulty in generating income or resources;
- invisible compromises to children's emotional well-being and mental health, and the risk that these are neglected in policy and intervention;
- severe adult illness and its potential to mediate the relationship with the child, and thus the child's mental and physical health;
- lack of knowledge among children about the nature and likely course of the illness, their exclusion from decisions around where they live and schooling, for example;
- gender- and age-based discrimination, and exploitation.

The latest data point to some unique aspects of children's caring roles in terms of well-being outcomes and the mediators in these:

- A heightened interdependence between the child and the sick adult as a result of the reciprocal nature of care;
- A raised sense of responsibility, especially at an emotional level and in terms of meeting daily household needs;
- The anticipation of the loss of a parent, or another close relative, often without full knowledge of the illness, its transmission or its implications for the rest of the family;
- Excessive time demands on children, which hinder their ability to complete homework, attend school regularly and move through the grades.

Three out of four of the above mechanisms, and a majority of the more general protective factors listed above, operate at the level of interpersonal relationships. This finding suggests the importance of policies and interventions capable of supporting the relationship between children and their 'caring' adults who may, in time, become those for whom the children care.

The quality of the relationship between child and parent-figure is the most effective predictor of child mental health.



Child-caring is not given specific attention in any of the four countries' policy documents, but remains a hidden, sometimes hinted at, component of AIDS-related vulnerability. Where mentioned, children's care roles are defined in relation to younger siblings in 'child-headed households'. Several national policies highlight children living with sick adults as 'vulnerable', and thereby of high priority. The strengths of the policies lie in their focus on improving access and quality of basic services to adults and children, and in this sense provide a robust foundation to resourcing child-carers.

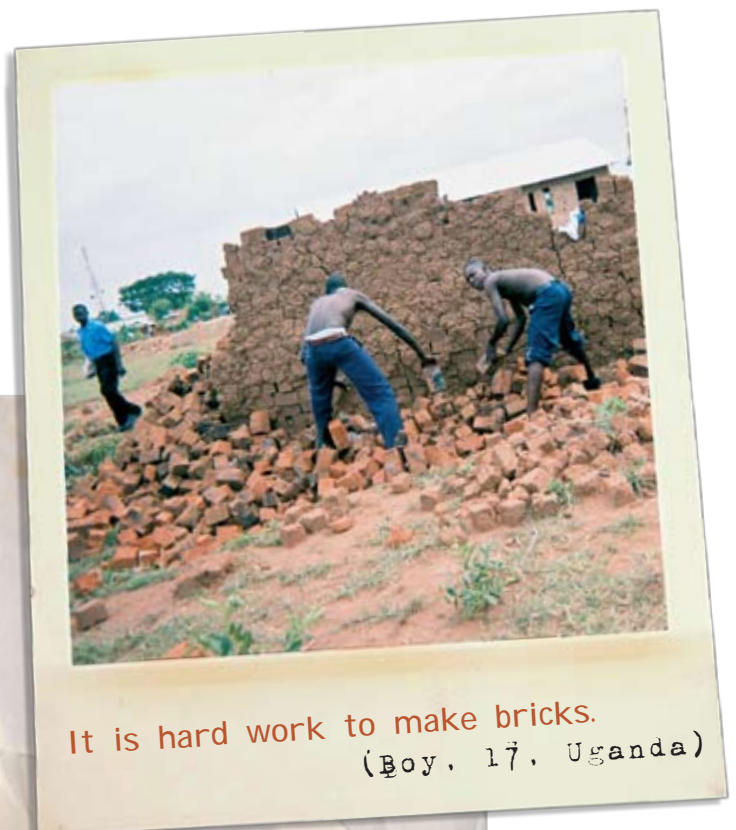
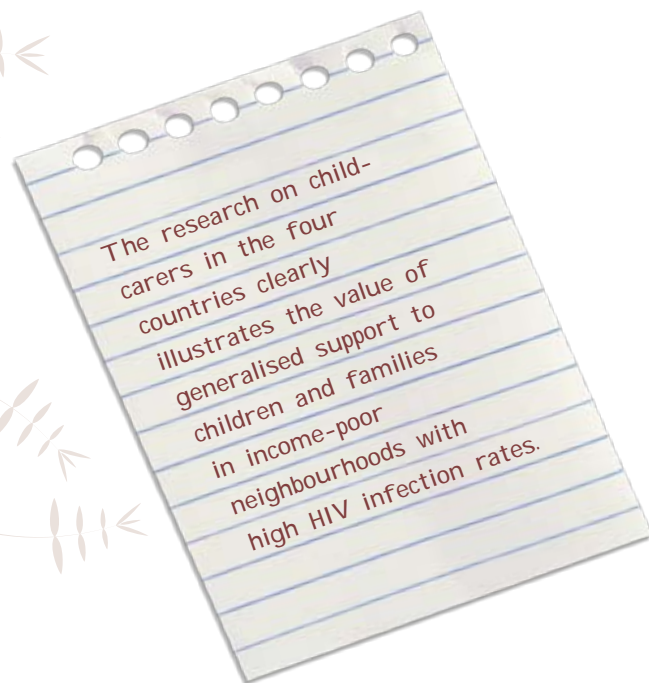
Four matters of substantive concern arise:

- 1. Absence of strategy to address psychosocial well-being:** Several policies draw attention to this as a priority area, but do not specify the means of addressing it. This implies limited knowledge of how to provide the nature and scale of the psychosocial support required.
- 2. Inconsistencies and contradictions around rights to parental care:** Nigerian and Ugandan policy for orphans and vulnerable children make explicit statements regarding the need for family reunification or 'alternative family care' for children in child-headed households. In Uganda, the second target group of vulnerable children includes those who live with sick parents. The goal of ensuring that children live in 'caring families' is stated, but the quality of caring is not defined. It remains possible that policy is -perhaps unwittingly- supporting the removal of children from homes where they are caring for sick parents. In Uganda, children's constitutional rights to know and be cared for by their parents stand to protect children in this regard, but require integration with existing orphan and vulnerable children policy.
- 3. Lack of clarity around the definition of child-caring as 'child work':** Only in Uganda has there been investigation of child work in the context of high AIDS rates. Even here, it is unclear whether the activities involved in caring, and the conditions under which children are performing them, are locally regarded as 'work' or qualify as 'hazardous labour' according to International Labour Organisation standards. The legal and practical implications of defining child-caring as child work have not been adequately considered.
- 4. Approach to service delivery:** Nigeria identifies orphans and vulnerable children and then targets them specifically with assistance. It is an approach that has been tried and largely rejected in other African settings, owing to its failure to respond to more general vulnerabilities found in a large portion of the young population, many of whom will become orphans. Uganda and Zimbabwe advocate a more integrated approach to enhancing service provision. Angola's policy provision is less detailed with respect to AIDS and emphasises approaches that are consistent with post-conflict rehabilitation. There are likely to be valid reasons for this, but the document is not supported by evidence that links post-war recovery and rising AIDS rates in terms of their respective or interactive effect on care in the home and on child well-being.

More pertinent, but less visible here, is the degree of political commitment to these and other policies that aim to protect children and their immediate caring relationships, especially in countries where long-held practices prioritise other ideals, such as the dual legal system that exists in Zimbabwe and the tendency for traditional law to hold sway, often to the detriment of women and children.

In the light of the paucity in knowledge on the topic of child-caring, an obvious recommendation is for further research. But large-scale prospective and longitudinal studies of the kind needed to thoroughly investigate the dynamics and outcomes of child-caring are not practical, being labour- and resource-intensive, and they would need to be repeated across diverse areas. It is recommended therefore that area-specific appraisals are conducted in each country in areas where child-caring is likely to be part of AIDS-related vulnerability. A profile of risk and resilience, an analysis of contextual factors such as migratory patterns and income sources and constraints, and a mapping of support services for adults and children should all be part of such an appraisal.

The research on child-carers in the four countries clearly illustrates the value of generalised support to children and families in income-poor neighbourhoods with high HIV infection rates. Appropriate psychosocial support within families – that is, bolstering the means to earn, to meet basic needs and thereby to protect mental health, and providing specific psychosocial support to children and adults to facilitate communication about illness, loss, grief and future planning – should also be included in this support.



Four Case Studies

The specific focus of the case studies was to find out:

- the reasons for children taking on caring roles
- their experience and perception of the caring role
- their perception of the effect that their caring role had on their relationships with the adults, if there were adults, in their household
- the challenges they faced as carers
- the support they received
- the resilience factors and stressors that they identified as present in their lives
- their ideas about support and interventions that would help them.

Nigeria

The research was done in Kafanchan, a town in the Kaduna State of Nigeria. Kafanchan is a town of about 83 000 residents 100 km northeast of the capital, Abuja. It was once a busy railway terminus, but with the collapse of the Nigerian railway service it has become a trading and agricultural centre. Half of the children came from a township, close to the town, that was originally built for railway workers. The rest came from a rural village where most people live off subsistence farming.

Angola

The research was done in the town of Huambo in Angola. During the Angolan civil war, the town was the site of struggle. Much of the surrounding rural population was displaced and still lives in the town. No family was left untouched by the war. Since its end, there has been extensive reconstruction of the town, but development of the surrounding farming area is much slower. The children came from the small houses built by displacees around Huambo.

Uganda

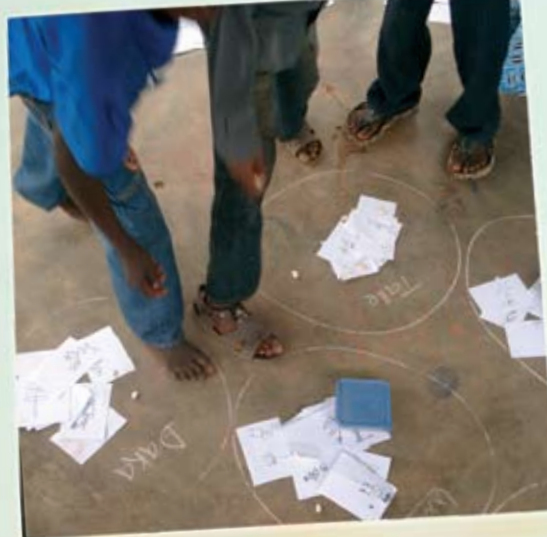
The research was done in the town of Nakasongola in Central Uganda. Half of the children came from homes around the town and the other half from a village close to Lake Kyoga. Most families in the area live off subsistence agriculture, though there is some fishing done by those who live close to the lake and a few opportunities for informal trading close to the town.

Zimbabwe

The research was done in Victoria Falls, a town on the northern border between Zimbabwe and Zambia. The town is a small tourist centre catering for the many thousands of tourists who come to see the famous falls. The children came from a township in the town and from a village in the nearby rural area.



Thinking about
photos that will tell
about my life



Using beans to show the
work done to earn money



Looking through the window

Research Approach

A local Non Governmental Organisation in each site identified a purposive sample of 12 children (six girls and six boys) of under 18 years and caring for a sick or very old adult or children. Most of the children selected were not receiving any assistance from a child-support organisation.² These 12 children then interviewed two or three other child-carers living in their area. A total of 124 children (61 girls and 63 boys) aged between 8 and 17 years participated across the four case study sites.

The first 12 children in each site attended a first, introductory workshop. In this workshop, they participated in a series of activities that allowed them to tell researchers about their lives as carers. They drew pictures of everyone who lived in their house and of their daily work. They drew a map of all the places they went to in a day, marking on it the places where they received support and help. Through role-plays and games they identified their burdens and concerns and the strengths they had developed as carers.

Each child identified two child-carers that they knew and could interview. They were also given disposable cameras to record their observations.

The child-researchers had two weeks in which to do the interviews, after which they attended a second workshop. In this workshop, they reported back on the interviews and described the photographs they had taken.

The information from the first and second workshops was tape-recorded and transcribed. The transcripts were analysed using a thematic analysis. Some of the themes that emerged are presented in the Findings on page 12.

Particular care was taken in this research to make sure that the work was done ethically. The Save the Children Child Safeguarding – Safe Child Participation Policy guidelines were applied before the research commenced. A set of general ethical principles based on a number of other guidelines was also applied.³

² Twelve of the children in the Nigeria case study site had very recently become part of the Fantsuam Foundation Orphan Support project. They received assistance with school-going, and some also received food support.

³ Boyden, J and Ennew, J (eds) (1997). *Children in Focus: A Manual for Participatory Research with Children*. Stockholm: Save the Children Sweden.

Clacherty, G and Donald, D (2007). Child participation in research: Reflections on ethical challenges in the southern African context. *African Journal of AIDS Research*, 6(2): 147–56.

Schenk, K and Williamson, J (2005). *Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources*. Washington DC: Population Council.

Child-led research

There is a growing commitment to children's participation in research about issues that affect them.⁴ Participation by children is particularly important – it gives us access to unique and essential information. Recently, there have been calls to extend children's involvement in research. As Kellett⁵ points out:

... much participatory research is still adult-led, adult-designed and conceived from an adult perspective. Children are party to the subculture of childhood which gives them a unique "insider" perspective that is critical to our understanding of children's worlds. Yet there is a paucity of research by children ...

In an attempt to extend the participatory nature of the research, this study incorporated child-led research. The child-carers who attended the first workshop identified their own research questions through a ranking exercise. They then learned about doing research, looking at how to ask permission, how to maintain confidentiality and how to ask questions. Through the use of the disposable cameras, they explored how photographs can tell stories. Then they interviewed child-carers that they knew and took photographs to record their observations.

The information that the child-researchers gathered added considerable depth to the data collected in this study. The children spoke more easily to the child-researchers than they would have spoken to an adult, often giving quite intimate details of their lives so it benefited the research. But as the quotes below show, the research activity also benefited the child-researchers. It gave them a sense of self-worth, it built their relationships with other carers and it helped them to see that they were not alone.

"This is a very important job you have given us. We are going to do it very carefully so many other people know about children like us. I think it is good that we go and talk [to the other children] because they know we are like them and they will talk to us."
(Girl, 14, Uganda)

"From the observation I had, I found out that the two children have similar problems like mine. Their condition is almost the same. It also has made me to know that I am not the only one with problems. There are other children who are suffering like me. I became stronger and more resilient." (Girl, 17, Uganda)

A lesson learned from the experience was that the younger children often struggled to explain to people why they wanted to take the photographs. Having a local adult who understood the process was highly important as, often, this adult had to mediate the researcher's access to the children they wanted to interview. The child-researchers also needed help in explaining that the camera was not for taking just any picture, but for recording the lives of the interviewees.

"A group of girls at the borehole wanted me to take a photograph of them. When I refused they shouted at me." (Girl, 17, Zimbabwe)

"On one day I gathered my friends to interview them. I was asking them to draw what they do, like we did in the workshop. On this day M's uncle was very angry with me that I gathered children and he said we are just playing. I was so surprised at his anger, but then I found out that M had just finished his household work quickly and ran out to meet us – that was why his uncle was angry. So I went and told Auntie R, who later talked to him and he understood why I am meeting with the children. That was how I was able to interview M." (Boy, 15, Nigeria)

The use of photographs as a research tool was particularly successful. The photographs gave the children a tangible recording tool that did not involve sophisticated literacy skills. They also allowed the children to record small, nuanced details of the child-carers' lives that enrich our understanding of the issues these children faced.

My young brother helps me to wash clothes. But my young sisters are still very young, so I am the only one who can cook. I am the only girl who can care for them.
(Girl, 16, Uganda)



4 Boyden, J and Ennew, J (eds) (1997). *Children in Focus: A Manual for Participatory Research with Children*. Stockholm: Save the Children Sweden. Grover, S (2004). Why won't they listen to us? On giving power and voice to children participating in social research. *Childhood*, 11: 81–93.

5 Kellett, M (2005). Children as active researchers: A new research paradigm for the 21st century? *NCRM Methods Review Papers*: NCRM/003. London: ESRC National Centre for Research Methods.

The photographs also allowed the children who were being interviewed to relate the issues they were discussing directly to their everyday lives; they saw the photographs very much as a tool for telling their stories. The extract below, from a transcript of a child-researcher in Kafanchan, Nigeria, illustrates the effectiveness of photographs as a data-collection tool.

A child-researcher from Nigeria reports to an adult researcher (R) on the interview he did with his friend, who is also a child-carer

"The name of the child I interviewed is V. He is 15 years old and his father and mother are both dead. He is in Senior Secondary II. They are four in their household. He has three other siblings whom he is caring for. He is like the father and the mother of his siblings."

R: Tell me about the photographs you took of V's life.

"V said the story behind this photo is to tell the caring work he does for his siblings in ensuring that their clothes are neat and tidy at all times. What he is doing in this photo is washing their clothes. He also goes to fetch water every day for them."

R: What about this photo, what is he doing here?

"V asked me to take him this photo, to show that he also pushes a wheelbarrow on market days. He said every Wednesday (which is the market day) he hires a wheelbarrow for N50 (50 Naira), and if he works very hard he ends up going home with N300 (USD2) or N400 (USD2.67).

R: What is this photo about?

"This is V selling fresh tomatoes and pepper in front of their house, and his siblings are the ones lying under the tree. He said with the money he gets from other work that he does, he buys fresh tomatoes and pepper and sells them in front of their house. Sometimes he could ask his siblings to watch over the tomatoes and pepper while he goes to do other things that would get him more money. He said he has no one to support him in paying of school fees, books and uniforms. He said he also has problems of school shoes. He said there was a term that he couldn't go to school because he took ill and he couldn't do work to raise enough money to meet his school needs, and no one could help him, so that was how he missed the term."

R: What about this photo?

"He said he mops their house every day, being the eldest in the house. His siblings can't do it, and for the sake of neatness he mops the house daily. This is V bathing their little sister, Jane, as part of the caring work he does for his siblings. He ensures that they are neat and tidy every day."

R: What is the story behind this photo?

"He said that he is the only one among his siblings that knows how to cook and he took this photo to show how he cooks for his siblings, when they have food in the house. He said it is always very difficult for him because whatever he is doing he has to leave it to come back home and cook."

R: And this photo?

"Together we play football in the field. He asked me to take his photo playing football as it is a means of forgetting everything around, to laugh and play with his friends."



I wash for neighbours to get money. I buy salt, half a kilo of beans, paraffin, books and pens. I use paraffin at night because my grandmother gets a bad attack at night and needs light.
(Boy, 12, Uganda)



I am going to school. I ironed my brother's uniform for him. It is behind the door.
(Boy, 11, Zimbabwe)



This is my grandfather's sister
planting groundnuts. When she is
feeling better she helps me.
(Boy, 17, Uganda)



I have to wash my uncle's
blankets. I need to wash them
almost every day.
(Boy, 10, Zimbabwe)



When I am feeling too sad and worried
about food and my sick mother, I go to
work in the garden. Then I feel calm.
(Boy, 16, Zimbabwe)

Findings

The following themes emerged from the child-carer research

Multiple and repeated caring

When looking at the nature of caring with regard to the children in all four countries, one of the first issues to emerge was that most of them cared for many people, some for more than one sick or old adult and all of them for young children. Many of the children had also cared repeatedly. Most of the children caring for old grandparents now, and all of those who were heads of child households, had looked after one or both of their parents before they died.

"I have the problem of looking after my grandparents and my sick mother. There are ten of us children too. My youngest sister is also sick."

(Girl, 17, Uganda)

My mother and my father passed away. I looked after my father and then my mother and then my sister came home and she was sick too. She passed away. Now I look after my little sister and brother and my aunt's child. My aunt has died. I also look after my great grandmother and my grandfather and grandmother.

(Girl, 14, Zimbabwe)



Drawing done by 14 year old girl who is quoted above

Boys and girls care

The sample of children who participated in the first workshop was purposive – there were equal numbers of boy and girls – but their statements made it clear that the girls and boys that they knew were carers. They easily identified boys and girls to interview about their caring roles. In Nigeria, 12 of the 19 carers they chose to interview were boys, and in Uganda 14 of the 24 were boys. As far as the children were concerned, boys were carers as often as girls.

"Boys and girls are caring.

If you are the eldest then you must look after the young ones.

If you are the only one there then you look for your grandmother – boy or girl.

I am a boy, but I look after my father who is sick and my little brother, and when my uncle comes home, him too sometimes." (Boys, Nigeria)

"Even if I am a boy and my mother is sick I must look after her. There is no one else. She is my mother." (Boy, 17, Zimbabwe)

Economic responsibility

Another striking theme was the way that the children defined their identity as a child-carer. For them, a child-carer was a child who worked very hard to make sure that the household had food and other essentials – the caring tasks related to illness were secondary.

R: So what does a child who is caring do?

"You have to work to get money for the family."

(Boy, 14, Nigeria)

"We are working hard to get money to eat because our granny is too old to get money for us." (Girl, 16, Uganda)

The children were also extremely clear that having a sick or very old person to look after placed an additional financial burden on them, as these people needed special food and medicines.

"I think that buying drugs for my grandmother is the worst thing I do. Because we spend all our money on them and they are expensive. We need to look for more money always for food." (Girl, 16, Uganda)

"Sometimes at the health desk they give you a medicine prescription for the child, but there are not drugs. You get the prescription and then you have to go and buy the drugs by yourself. I have to do small jobs to earn money to pay for the drugs which we are going to buy." (Girl, 13, Angola)

The notes on this page outline the types of activities that four children in the Nigerian and Ugandan case study sites did to earn money. These children were typical of the children in all four case study sites as they did multiple tasks to earn money for basic needs. In the four examples, the children did this work and attended school.

(Boy, 14, Uganda)

Making charcoal
Making ropes
Digging for neighbours
Working as a porter at a building site

Boy, 14, Nigeria

Pushing wheelbarrows of goods from town
Fetching water for neighbours
Fetching firewood for neighbours
Fetching sand from the river to sell
Farming for people

Girl, 17, Uganda

Fetching water for neighbours
Digging for neighbours
Helping a neighbour who makes local beer
Making charcoal

Girl, 12, Nigeria

Selling boiled groundnuts
Buying and selling sugar cane
Making and selling burukutu (local beer)
Fetching water and selling it
Cooking yams to sell



I look after the animals for a neighbour.

(Boy, 11, Uganda)



This is what B does to earn money to support himself. He is an auto bike mechanic. He usually goes there every day after school and after all the household chores that need to be done.

(Child-researcher reporting on a child of 12, Nigeria)



I catch fish and sell them. A kind man I know lends me his boat for this.

(Boy, 10, Uganda)



I dig in the neighbours field and he gives me food.

(boy, 15, Zimbabwe)

A challenge the children mentioned was the fact that the work they had to do for money was often very hard and heavy work.

"The collecting sand is very hard work. It depresses me to the point of having to be sick and the load is very hard."
(Boy, 13, Nigeria)

In Zimbabwe, where economic collapse had made informal work almost impossible, the children worked hard to find basic needs, such as food (usually enough for one meal). They also spent a lot of time going around asking for food.

"I just go around and ask neighbours. We borrow and beg from neighbours. If they don't have we just stay like that. At times the neighbours give you, sometimes they don't. The neighbours will say they are tired of us asking for food." (Boys and girls, Zimbabwe)

It was evident that every child we worked with did not have the capacity to meet the basic needs of their households. In spite of the work that they did, they did not earn enough even for food. Being hungry was an issue all of the children raised.

"This picture is telling my story of one of the caring activities I do. It is making sure I cook for all my family members. I cook once daily, which we eat in the evening and in the morning. Mostly in the afternoon we do not eat and some days we don't even eat at all when there is no food in the house." (Boy, 13, Nigeria)

"Sometimes we spend a week without food. The most important season to us is the season of the mango, where we can just pick up a mango off the tree and eat it. Mmmm. [the other children all agree] I cannot wait for mango season. Sometimes there is no food to eat at all. Other children eat three good meals a day, but sometimes we don't eat at all." (Boys and girls, Nigeria)

They also talked about having no money for soap or clothes, or blankets. They struggled to mend their homes, which often leaked when it rained, and they had enormous problems with money for school. Another issue was that many of them had lost land when their parents died, so they did not have enough land to grow their own food. Some even had to find money for rent.

"When my parents died, my grandfather had a piece of land, then someone can say your grandmother is no longer able to speak, so you should move from this land, this house, and get a rented house where you will keep her. So we have no land." (Girl, 16, Angola)

"There is someone who came to buy. They gave us a smallest portion like one room and a toilet, while we had a big land for the family, so that's why the rent is a problem. Now we have to pay them rent." (Boy, 12 Uganda)



Here I went to do washing for neighbours and they pay me.
(girl, 14, Angola)



Household and caring work

As well as working for their basic needs, the children all had to do household work, such as collecting water and firewood for their own homes. For those children who lived in households where there were only young children, this work was considerable, as the younger children could not help with much of it. The drawing below shows the household tasks this child does

before she goes to school in the morning.

R: But don't all children do housework?

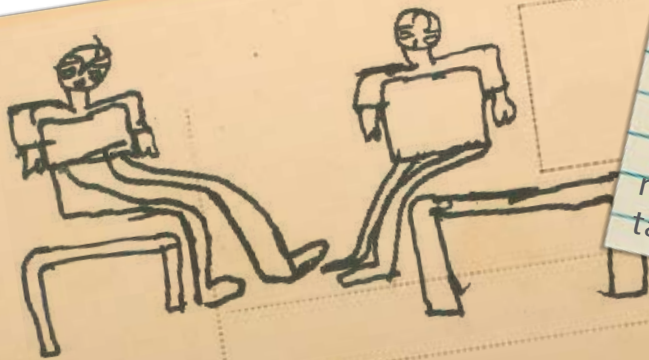
"We are doing more than others because of sick people – like washing blankets.

We don't have people to help us with these jobs. Like firewood or even washing for the children."

R: Who usually helps with these jobs?

"Parents." (Boys and girls, Nigeria)

Like this photo shows
I was mopping the
room where we lie
because sometimes
if my mother is too
weak she vomits inside
the room, so I have
always to mop the
room so that the room
can be neat and tidy.
(Girl, 15,
Nigeria)

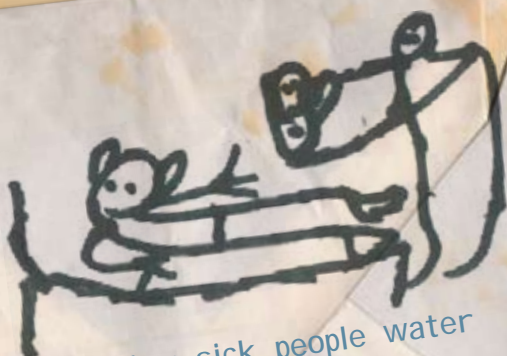


Staying close to them and
telling them stories

Buying drugs
for the sick and
making sure they
take them

Cooking special food for
the sick and old

Cooking for sick one



Giving sick people water

Washing clothes
and blankets for the sick people



**"I have to try every way
to get food for my grand-
mother as she is too old."
(Boy, 17, Zimbabwe)**



Washing the
little children

Only once the children had talked about the heavy work they did to earn money did they begin to describe their caring work. They performed a wide range of caring tasks, from cooking special food for the ill people to bathing them, taking them to hospital, fetching drugs, making sure they take their drugs, talking to them and cheering them up. The drawings on page 16 and above show some of the caring tasks the children in the Nigerian case study site identified.

One of the biggest issues related to their caring task was cross-gender caring. Boys talked about how difficult it was to wash their old grandmothers, and girls talked about the difficulty of washing their fathers or brothers.

"B looks after his disabled mother, and he says it is difficult to take care of a parent of the opposite sex, as sometimes or often he has to bath her." (Child-researcher reporting on an interview with an 8-year-old, Zimbabwe)

"I only wash my granny's feet and hands. But it is a problem to wash the whole body. It is very difficult to wash the whole body. And you cannot tell anyone about it." (Boy, 16, Zimbabwe)

"It is hard when you are looking after your mother and she has the call of nature and you have to accompany her. I am alone and I am a boy, but I have to wash my mother's clothes, there is nobody else in the house. I feel troubled because I think if my mother had not been in this situation I would not be feeling this. I think that if my mother had been well she would be looking after me, not the other way round." (Boy, 15, Angola)

The children worried that they did not know how to look after the ill people properly. Another issue that they commonly raised was their fear of contracting HIV. Very few of the children knew for certain that their parents were ill with AIDS, but many guessed they may be.

"Their mother did not tell them, but they hear from the neighbours when they are discussing about them." (Girl, 16, Uganda)

"Another problem is we don't know how to care for sick people."

R: What would you like to know?

"The types of drugs to be taken and how to care for that sick person or the old people."

There are some people who come to talk about HIV and AIDS, they just move around and talk and then go away.

Nobody has shown me how to care for the HIV person. I would like to know about treatment."

(Boys and girls, Uganda)

The girl interviewed is worried that the sickness might get to her. Maybe it is AIDS.

She might be worried about it. She might also worry about hepatitis".⁷ (Boys and girls, Nigeria)

The children in all four sites showed no resentment at all in relation to the burden of work they carried. In fact, they took pride in how well they cared for the young children, and many said they enjoyed caring for their old grandmothers and ill parents because they loved them.

"This is the room we stay in with grandmother. I am mopping it so that it could be clean, so that grandmother can be happy because she stays indoors most of the time." (Girl, 12, Nigeria)

"We love them so we feed them and bath them, washing the sick clothes. We take them to the latrine because they can't walk alone, they need support. They are our grannies, we need to support them." (Boy, 17, Uganda)

"I have to try every way to get food for my grandmother as she is too old." (Boy, 17, Zimbabwe)

When asked which of their tasks they wanted to be removed, no child in any of the four areas chose the caring work they did. Consistently, the work they wanted removed was the hard and unrelenting effort to earn money.

"Early in the morning I feel very bad because you haven't done any work yet, but you think about it. You feel the weight.

Yes, you wish it was not there.

Even when I am in bed I cannot sleep because of thinking of all the work. Sometimes I am sleepless because of thinking." (Boys and girls, Angola)

6 In order to keep confidentiality, we allowed the children to discuss their fears about looking after someone who has AIDS by using a set of silhouette figures. Even though the children refer to other children in these statements, they are very likely recounting their own experiences.

7 The same applies here.

A 12-year-old child-researcher from Nigeria reports on an interview she conducted with a 15-year-old girl

Why children are caring

From the children's point of view the main reason they had the responsibility of earning money for their families and carrying out caring tasks was because there was no one else.

"You can't choose. Because if my mother is sick I don't have the choice to say I can't do it, because it has to be done.

I can't choose because there is no one who is going to do it besides me. It's a must. Because if you don't cook you can die of hunger and your granny can die as well." (Boy and girl, Zimbabwe)

Adults that we spoke to in all four case study sites⁸ were clear that the situation of children as sole carers was not a cultural norm, but rather a result of the loss of the middle generation to HIV/AIDS.

"It is not the culture [that young children look after the grandparents]. The tradition is that the parents should care for the children. It is a condition caused by the parents having to die and leave grandparents to take care of the children.

The children have no choice.

It is because of AIDS." (Adults from a local village support group, Nigeria)

Problems with school

After money for everyday needs, the biggest challenge for the child-carers was finding resources for school. It was a challenge for those that went to school and for all of the younger children they looked after. Being sent away from school for not having the correct resources was their main reason for missing school.

"I told me about the problems he has at school. Sometimes he is sent away from school because of fees and uniform. He also lacks books. He doesn't have anybody to help him. He does everything by himself. Sometimes he sells a chicken when he is in crisis. Or he works for some days to get the money and then goes back to school." (Girl, 16, reporting on her interview with a 12-year-old boy, Uganda)

One of the older boys said that the main reason he had left school was to earn money for the younger ones to continue going to school. Another boy talked about how he often thought of leaving school because he needed to earn money for the family. He took a photograph of a friend who helped him and persuaded him to try and stay in school.

"M is a girl who is caring for her grandmother. She left school at Primary 6 because she couldn't pay for her common entrance into secondary school. Before then she used to hawk sugar cane when it's the season, but her grandmother saw the difficulty and the suffering in hawking. She asked M to stop hawking and pick up a job as a house-help to a family close to their house."

R: Now that she is out of school, did she tell you how she feels about it?

"When I was asking her about schooling, she started crying, so I had to stop asking her."

R: Oh, I am sorry. It was good that you stopped asking her. What work does she do?

"She goes to work as house-help and closes by 12.00. Then she comes home to cook, bath her younger brother, fetch water for the grandmother and the entire house. From the proceeds of her work she supports the grandmother with medicine and food. She said there is nobody that helps them, aside from her friend close to their house, who sometimes helps them with food."

"The second photo is my friend who gives me advice and supports me morally. Here in the photo we were discussing. We go to school together in the same school. One day I wanted to leave school because of problems, but my friend advised me not to do so. Sometimes he gives me some money when I have a money crisis. He is not like me, he has parents."

(Boy, 16, Nigeria)

Children also missed school because they had to stay at home to look after an ill person or go to the clinic to get medicines for the ill person. Being late for school because of household and caring work and finding time to study were also troubling issues for many of the children. Another issue was that they had so much to do when they got home from school, they often only managed to get to schoolwork very late.

⁸ In each case study site, we spoke to a group of between 15 and 20 adults from the local community about children they knew who were caring for someone.

This photo shows I was doing my schoolwork. I have only one small time to do schoolwork. There is a lot of work to do every day and only after it is done can I do the schoolwork.

(Boy, 17, Zimbabwe)



Support and discrimination

Few people knew that the children were caring. The children in the first workshop drew a map of their area and then marked those people who knew that they were caring. Most children marked two or three people (or groups of people): the immediate neighbour, a friend (who was often also a carer) and the church. A few of the children had an extended family member who helped when they could.

Neighbours sometimes helped, mostly by giving small things like salt. A few times, children mentioned that neighbours gave them food, or jobs to do in exchange for food. Institutional support differed from country to country. In Nigeria and Zimbabwe, some of the children received support from local NGOs, but there were no NGOs operating in Uganda, and the NGOs that worked in Angola did not focus on child-carers. Churches were the most common form of institutional support. Many of the children talked about churches giving practical and emotional support. A few children had teachers or principals who were supportive. Some children received no support at all.

"Nobody helps me. Each person has his/her own problems. The people in the community have changed their attitude. Each one minds about himself/ herself. Nobody helps me." (Boy, 17, Uganda)

The children agreed that their friends were their greatest support. Many of these friends were also child-carers, who understood their situation. They gave not only moral but also practical support.

"They feel sorry for us. Some of the time if there are functions at school they pay for us.

They also give us advice.

They say, 'Don't worry too much. One day you will rest, like other children.'

My friend advises me how to use my money. She says if I get money from my aunt I must buy food and with the remainder I must buy clothes.

Sometimes they help us in fetching firewood and water.

My friend is also caring for her grandmother, and she helps me when my grandmother is sick.

Yes, they understand if they too are caring."

(Boys and girls, Zimbabwe)



This drawing is typical of all of the groups. The drawing shows all the places the child went to in a week. The black circle shows people who knew the child was caring - the church. The X shows those who knew and gave support - the house of the child's friend. The black line drawing in a circle shows another child who knew that the first child was caring and who was also a child-carer.

"My little sister helps me to do the work. She sometimes washes the clothes and helps me to fetch water."

(Girl, 15, Zimbabwe)

All of the children talked about the discrimination they experienced from adults and peers. They were discriminated against because they were poor and had old clothes and no money for soap, because some of them did not go to school, and because they were looking after old and sick people. There was a lot of discussion about discrimination related to gender roles.

"The condition at N's home is not good. They laugh at her because of the caring roles she plays at her home, being a girl and doing different activities to maintain the home. She also does tasks which are supposed to be the men's work, like burning charcoal. The children ask her why she does not leave and get married – so must she leave her young brothers and sisters and her mother just suffering?" (Boy, 16, Uganda)

"Making charcoal is a boy's job. They laugh at me. They laugh and say, 'Look at this woman. Stop doing that. Come, we will give you money.' And that money will mean something else, it's not free money [it is money for sex]." (Girl, 17, Uganda)

The other main discriminatory issue was that they were often caring for people who were ill with AIDS.

"I feel angry when someone insults me."

R: How do they insult you?

"They are saying, 'Your mother is sick with AIDS.'

Yes, I get angry when they say, 'Your mother used to go to night clubs and now she is sick.' People say, 'Go away with your mother who is sick.'

Yes, some people say to me, 'Your mother's grave is ready.' Others are saying, 'When your mother dies, we want to eat meat and not cabbage [a reference to the food provided at a funeral].'

Like at school they call you a fool and say you are looking after a sick person that is why you are a fool. Some say, 'You are looking after a sick person and you will get infected too.'"

R: So how big is this insulting problem? (Researcher uses her hands close together and then wide apart to show a scale)

"This big!" [All the children show her their hands very wide apart, indicating that it is very big.] (Boys and girls, Zimbabwe)

Relationships in the child-carer household

The strongest relationship in the family seemed to be between siblings. All of the children talked about how they supported each other in the earning and caring work they had to do. They also gave each other emotional support.

"We are coming from the well to fetch water with my brothers and sisters in this photo. We also dig in the garden as a small team to get money to buy clothes." (Girl, 15, Uganda)

"My little sister helps me to do the work. She sometimes washes the clothes and helps me to fetch water." (Girl, 15, Zimbabwe)

The relationship with the adults for whom the children cared was significant. Most talked about how they loved the people they cared for and how they looked after their emotional needs, by talking to them and bringing them news. They also discussed the strategies they used to get them to eat or to take their medicine.

"We are talking to them while they lie on their beds. Yes, we give them information about what is happening in the community, but not stories as such – what we heard has happened, someone who is sick or who has died." (Girl, 15, and boy, 17, Uganda)

"Sometimes you are just sitting and talking. Then the time for the pills comes and you remind them of the medicines. Then they be would complaining, 'Why are you reminding me of the medicines?' Then I would say, 'Because I want you to be strong and fit.' Then I would ask, 'Where are the pills? I also want to drink.' I take the medication and pretend as if I am drinking the pills, so she would drink her tablets." (Girl, 9, Zimbabwe)



On the whole, the children's grandparents and parents reciprocated this love. Many children talked about how their grandparents worried about all the work they did and that they created more work for them. Some told stories about how their grandparents tried to do a little work to help them. The children noticed and appreciated this.

"When the grandfather is not sick he usually helps with some of the work. Sometimes when B comes back from school, the grandfather would have cooked." (Child-researcher reporting on an interview with a 16-year-old boy, Zimbabwe)

There was also evidence of parents and grannies playing an ordinary parenting role – giving advice, telling stories and making jokes with the children.

"Our granny tells us stories."

R: Stories! Okay. About what?

"About the former leaders of this country, how they ruled. About the way they used to work and to eat. My granny tells funny jokes."

R: She does?! Like what?

"She would say, 'Come, I'll carry you', while she knows that she can't, so that's a joke." (Boys and girls, Uganda)

R: Why did you take your mother's photo?

"My mother is very important to me because she is the one remaining and supports me morally, although she is sick. I wanted to show people my sick mother and the condition and what we do for her. In this picture we are all having a meal with our mother, around her. We eat together so that she gets appetite to eat." (Boy, 16, Uganda)

"My granny asks me about what did I write at school today, how was school today, everything. Do I have some books." (Boy, 10, Zimbabwe)

"My mother does normally advise me as a boy not to rush to marriage because I can make mistakes. I should be sturdy and look for the right person to avoid infection. My mother, too. She talks about how I feel. We normally discuss issues. She advises me to look after myself so that I won't be like her, that I should secure a good marriage." (Girl and boy, Zimbabwe)

However, the children were also honest about the stress of looking after an ill person.

The importance of a good relationship

J is a boy of 15. He participated in the workshop with quiet intensity, concentrating on the drawings and listening when we had a discussion. When we discussed the caring tasks that the children did, he talked about his aunt whom he cared for.

"I sell things to help my aunt. I have to go every day up and down to sell to try to get money for food. She cannot do anything. She was injured in the war. Her head and her stomach. She gets very bad headaches and she cannot carry anything. I have to help her with the collecting of water, everything. I like the selling because it helps us. It helps my aunt."

When we took the children home after the workshop, J showed us his home. He lived in a small mud house just outside the town of Huambo. As we arrived, his aunt came out to greet us. She put her arm around J. Their relationship was clearly a close one. She then began to tell us about what a good boy he was. She had found him as a small boy when his village and home were destroyed in the war and he had lived with her ever since. Following her injury, J looked after her.

"I would not be alive but for this boy!"
As we left, they stood at the gate to the courtyard and waved to us.

"Sick people are always difficult to manage. She is always sensitive and always gets wound up. I have to be careful in whatever I do for her so that I do not annoy her. For example, if I don't find medicine in the clinic she becomes upset easily." (Girl, 15, interviewed by a child researcher, Uganda)

Resilience and stress

There was evidence of both resilience and emotional stress in the children. Perhaps the greatest strength the children showed was the sense of responsibility they had to the young, old and sick in their care. They worried about the lack of food and the lack of school requirements for the young ones. They worried about getting drugs for the sick, and they wanted to earn enough money to buy necessities.

In comparing themselves with other children who were not carers they agreed that they had a greater sense of responsibility. They also felt they had more skills. They certainly had parenting skills. They also had strategies for dealing with the sick or old person they cared for.

"The next photo is my young brother washing plates and cups. He is six years old. I have taught him to wash utensils so as to help me with the housework."

(Girl, 15, Uganda)

"If a sick person shouts at me I become soft [gentle] and they calm down, they cool down." (Boy, 16, Nigeria)

R: What about if the children are feeling sad, what do you do?

"You counsel them so that they get happy. You prepare food for him and the child will speak for himself. The child will speak for himself how he is feeling. Sometimes he feels the pain, but you need to see what is troubling the child." (Boy and girl, Angola)

The children also talked about how they coped with their at times overwhelming responsibility.

"Sometimes I look for the piece-work and they give me. Then the following day I go back and they say there is no work and I get sad. When I get sad I go to the garden.

I go to the trees and sit there.

I go to my friends to play a little bit and I feel better." (Boys and girls, Angola)

"Sometimes when there are lots of things to do I feel like hiding. I look for a place to hide away from the house. Some hours after that I come back. Hiding does solve the problem because when I come out I feel calm. We do tell some friends and it helps." (Boy, 16, Uganda)

"I know how to make myself feel better. I get happy when I play with my friends, when I get time to play and forget. I always listen to music on the radio and that makes me to feel happy. When a friend comes I also feel better." (Boy, 10, Zimbabwe)

As well as these strengths the children had many stressors. They talked about how they felt angry and sad when they thought about their situation as carers.

"It's a combination of things, like the grandfather is sick, the mother is sick, we don't have money, the firewood is not there. Everything is on you, one person. Sometimes I feel like crying, when I come back from school and they tell me that this is not there, that is not there.

We sometimes cry. It's because of feeling a lot of pain without help." (Girls, Uganda)

"Sometimes you feel like running away from it [the caring] when your friends come for you to go and play, but you just can't go because she [the child's mother] is going to be sicker for you.

Sometimes you go and play, without having given the tablets, so it will come back to your mind that you have not given the person the tablets. It keeps coming to your head." (Girl and boy, Zimbabwe)

"I get very worried when we need something and I don't know where to get it. I think, 'What will I do tomorrow as others have seed [for planting] and I don't have. What should I do to get some?' My worry is, 'What are we going to eat? When will I have my own things? When will this be over?'" (Boy, 15, Angola)

The children described how the stress was often worst at night. Many reported having trouble sleeping and bad dreams, usually related to the loss of their parents. They also talked about how they thought a lot about the death of their parents. Another common fear was around the death of the person they looked after – what would happen to them if the person died?

"The reason for her to worry is that when her father dies there will be nobody to look after her and the family." (Girl, 15, Nigeria)

They all agreed that no one had discussed death or their future with their parents or grandparents, even though they worried about it.

"The condition is not good at this home because N told me that she was worried. The father died and the mother is also sick. N is very worried about the mother. She might die and N would be left alone. The relatives are not many and are not caring at all."

R: Did you ask her whether she discusses with the mother about death?

"N said that she didn't want to talk about it. In her discussion she said it was not possible because it would worry the patient. Even myself, I can't talk about the death with the sick. It is not possible. It can upset the patient and scare him." (Child-researcher talking about a girl of 14 Uganda) 📌

Recommendations for Policy and Programming

Clearly, the 124 child-carers who participated in this study carried a heavy practical and emotional burden. However, they also developed certain practical and emotional strengths.

We know from recent research on resilience that children need certain factors in their lives if they are to overcome difficult circumstances and emerge as healthy adults⁹. Fergus and Zimmerman¹⁰ talk of these resilience factors in terms of assets and resources:

Assets are positive factors that reside within the individual, such as competence, coping skills, and self-efficacy. Resources are also positive factors that help youth overcome risk, but they are external to the individual. Resources include parental support, adult mentoring, or community organizations

Most of the resilience factors the child-carers had took the form of inner resources. They had a strong sense of responsibility, they were able to seek out help from the few sympathetic adults they knew, they were able to problem-solve in order to make a living out of various tasks, and they could solve problems among the children at home. They also showed maturity and emotional strength in the way they parented younger children.

Bray¹¹ (2009) demonstrates that a positive relationship with the person they care for is an important resilience factor in the lives of child-carers. It appears that many of the children in the four case study sites indeed had a largely positive and supportive relationship with those they cared for. It was probably partly from this resource that they developed the inner strength that allowed them to continue with everyday life. Significantly, some

of the children did not have this resource. A few of them also had support from friends and other child carers they knew.

But for most of them the other resources that promote resilience were largely absent. They had no help in accessing their everyday needs and carried the heavy burden of working to earn money and find food. They had little support from adults or other children in their community. They did not have easy access to health facilities or to information that would have helped them



9 Fergus, S. and Zimmerman, M.A. (2005) Adolescent Resilience: A framework for understanding healthy development in the face of risk. Annual Reviews of Public Health 26: 399-419.

10 p399

11 Bray, R. (2009) A literature review on child-carers in Angola, Nigeria, Uganda and Zimbabwe. Save the Children UK: Pretoria.



with their caring responsibilities. They were deeply committed to going to school, but the institution itself placed many insurmountable – as well as unnecessary and/or incomprehensible – barriers in their way.

Various risk factors were also present in their lives. The heavy work they had to do placed them at risk both physically and emotionally.

The discrimination they experienced, particularly that directed at their gender identity, affected their self-esteem. Their emotional stress was evident in their sleep difficulties, for example. Much of this stress seemed to be related to grief that they could not deal with in the face of multiple deaths. They often felt as if their responsibilities were overwhelming.

They had no access to accurate information to protect them, or information about the illnesses their parents had and the likely outcome. They had little institutional support in their caring responsibilities. The peer-support they had was informal and created by them. They had few adult role models or mentors.

It is this lack of outside resources that should be the focus of advocacy. Advocacy needs to take place at a regional level – through initiatives such as the Regional Inter-Agency Task Team on children and HIV (RIATT), and at a country level – with national, district and community government and with local NGOs.

The advocacy issues are as follows:

1. The need for interventions that will reduce the heavy burden of economic responsibility that these children carried. There are many examples of such interventions – cash transfers, micro-financing to start income-generation projects and vocational training have all been attempted in various contexts. Given the fact that many of these children are still in school and committed to school-going, cash transfers of some kind may be the best option. The Humuliza programme, which gives a form of cash transfer to orphaned children, and the KwaWazee

programme¹² (www.kwawazee.org) which gives a cash transfer to grandparents, operate in a similar context to the four case study sites and could therefore be useful models to apply at a local level.

2. The need for easier access to schooling for vulnerable children. Education of principals and teachers about the lives of child-carers, and indeed legislation (that is enforced) to make schools more accessible, should be put in place.

3. The need for education, information and support for child-carers around how to care for old people and people who are sick. Child-carers should receive training and support from community home-based care programmes. Such access to knowledge and practical support would lessen the burden of fear with which they live. Accessing medication is also a huge burden for these children. Organisations lobbying for free access to treatment (particularly for those with AIDS) need to include the fact that the payment for drugs is taking money that would be used for food and other basic necessities in child-caring homes.

4. The need for programmes that provide psychosocial support for child-carer families. As the literature review points out, relationships within the family are an important protective factor. Psychosocial support for families is important. Children also need their own support groups. The research shows that children already use peer-support as a coping strategy, and that often this support comes from other carers. Local support groups, where child-carers meet regularly, would therefore be effective interventions.

It is important that advocacy efforts around vulnerable children acknowledge child-carers – this particularly vulnerable group of children who have largely remained invisible until recently. It is hoped that the pilot programmes (see page 25) that arise out of this research in the four countries will provide organisations like Save the Children with information that elicits targeted advocacy around the best form of intervention for child-carers.

12 Hofmann, S. Heslop, M. Clacherty, G. and Kessy, F. (2008) Salt, soap and shoes for school. Evaluation summary. The impact of pensions on the lives of older people and grandchildren in the KwaWazee project in Tanzania's Kagera region. REPPSI, and World Vision International and Help Age International: Dar es Salaam

A pilot programme to test a model of local support for child-carers

The Ford Foundation grant for this work makes provision for the implementation of pilot interventions, based on these research findings, in the four countries in which the research took place. The nature of the pilot intervention was discussed with the relevant Save the Children staff. Here follows certain recommendations for the pilot, based on the research findings above and the discussions.

Income-generation projects, vocational skills, information and psychosocial support

The children identified the need for immediate help with their economic situation. Local staff suggested that the best way to achieve this is through income-generation projects. Many of the children were already involved in small income-generation projects. They identified poultry-keeping (which some of them already did) as one of the best ways to make money.

They also mentioned their concern about their future because of their lack of education or the difficulty they will have in accessing any kind of further education after school. This points to the need for vocational training that would allow them to look after their families effectively as they grow up.

Furthermore, they described signs of significant emotional stress, which suggests the need for psychosocial support to help them cope. They also wanted information about how to care more effectively for their parents and grandparents. The proposal for a pilot therefore includes all these elements.

Income generation

The pilot should include setting up support groups of the children who were part of the research (both initial researchers and the children they researched).

This support group should include an initial training on how to start a small business. These businesses need to be appropriate to the area in which the children live. Once they have received the training, they should be given a loan to start the business. They would then need monitoring and support, and should pay back the loan over time. They should have the opportunity of borrowing more once they have paid back the initial loan. This finance should be set up as micro-finance projects are set up (see Humuliza, KwaWazee at www.kwawazee.org in Tanzania, and the Fantsuam Foundation www.fantsuam.org in Nigeria for examples).

Vocational skills

Once the business is up and running, the children who are not in school should receive support in getting vocational training. Local vocational training organisations/institutions should be accessed for this as far as possible. If these are not available, placements in local businesses should be researched. The children should be involved in this process. This vocational training needs to continue so that the children who leave school in the next two years are also able to access it.

Information and education

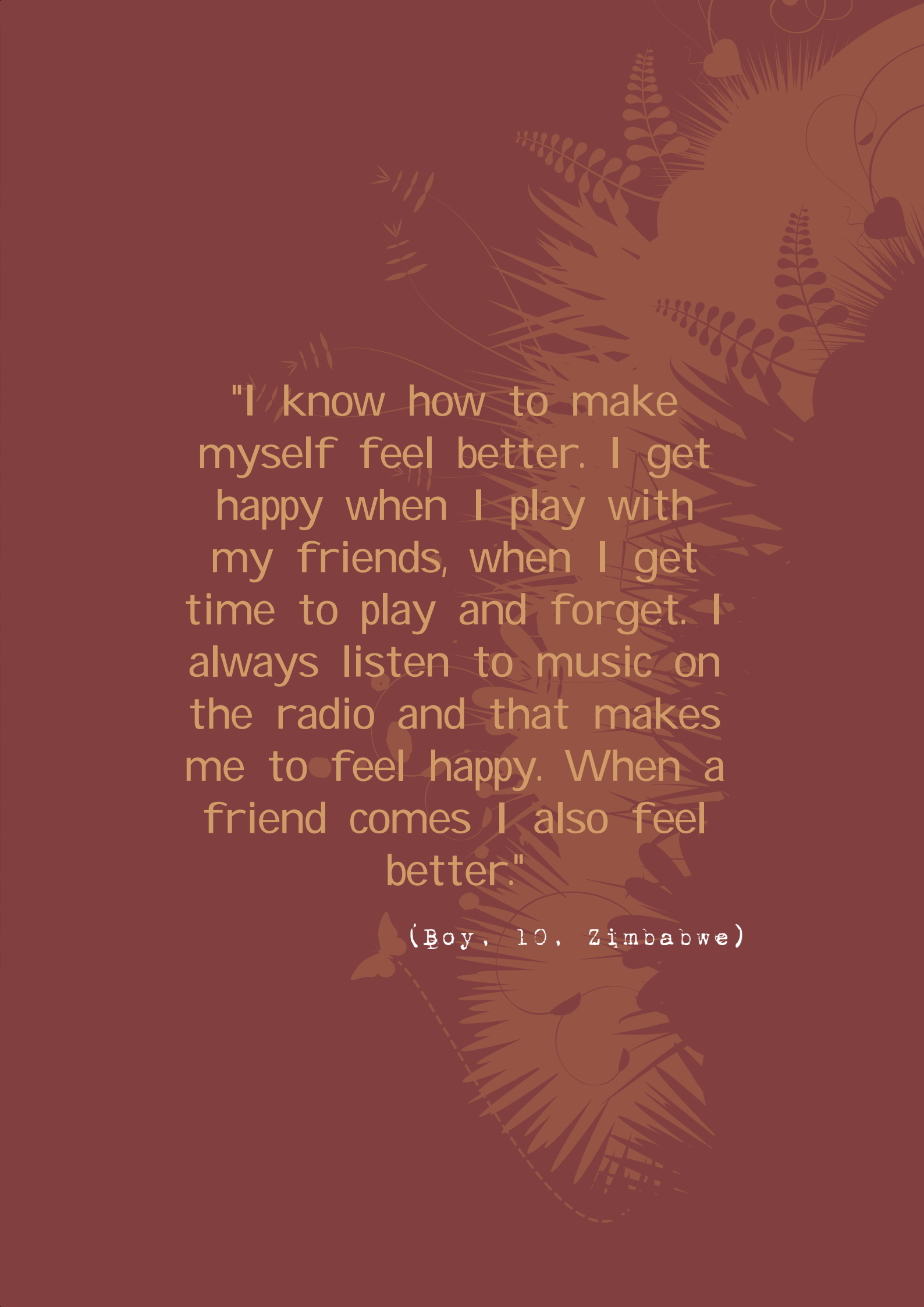
An education programme that provides information about how to look after old and ill parents and siblings needs to be developed. The Symphasis programme for child-carers presently being piloted by Kurt Madöerin in Tanzania could serve as a useful model for this. Local NGOs which are involved in home-based care in the area need to be brought into this programme, as they would need to provide ongoing support to the children.

Psychosocial support

The group should meet regularly. Initially, the meetings should be structured by an adult facilitator. The activities could be based on the abovementioned Symphasis model. After six months of such input the group should receive training in setting up a child-led organisation similar to that of the VSI (Humuliza). Clacherty and Donald¹³ suggest that this kind of organisation has a significant psychosocial impact in its own right. The adult facilitator should slowly withdraw and the adult support should then be to monitor and build the capacity of a child-led organisation. ☺

13 Clacherty, G. and Donald, D. (2005). Impact Evaluation of the VSI (Vijana Simama Imara) organisation and the Rafiki Mdogo group of the HUMULIZA orphan project Nshamba, Tanzania. Clacherty & Associates: Johannesburg





"I know how to make myself feel better. I get happy when I play with my friends, when I get time to play and forget. I always listen to music on the radio and that makes me to feel happy. When a friend comes I also feel better."

(Boy, 10, Zimbabwe)



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