Is this ‘coping’? Survival strategies of orphans, vulnerable children and young people in Zimbabwe

ELAINE CHASE¹ KATE WOOD² AND PETER AGGLETON³

ABSTRACT
An in-depth study of the coping strategies of orphans and other vulnerable children (OVC) affected by HIV/AIDS was conducted across six sites in rural and urban Zimbabwe. Qualitative methods including case studies and in-depth interviews were used to examine the daily lives and coping strategies of children and their families. Data were gathered primarily from children and young people, but also from adults in families and communities. The research identified considerable hardship for most interviewees as a result of HIV/AIDS combined with the harsh economic climate in Zimbabwe. A range of both positive and negative coping strategies were employed by children and young people in response to the difficulties that they faced. Considerable resourcefulness, innovativeness and resilience were observed in relation to securing basic commodities and sustaining households. The extent to which children coped with the emotional and psychosocial impact of HIV/AIDS was more difficult to ascertain, and scant consideration was given to these aspects of their lives by adults in families and communities. The research concludes that HIV/AIDS programming must ascertain the extent to which children cope with both the practical and psychosocial impact of HIV/AIDS, and respond accordingly. This can only be achieved if children living with and affected by HIV/AIDS are engaged more centrally in programme development.

¹Research Officer, Thomas Coram Research Unit, Institute of Education, University of London. (Author for correspondence). Email: e.chase@ioe.ac.uk
²Research Officer, Thomas Coram Research Unit, Institute of Education, University of London. Email: k.wood@ioe.ac.uk
³Director, Thomas Coram Research Unit, Institute of Education, University of London. Email: p.aggleto@ioe.ac.uk
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HIV and AIDS, vulnerability, children, young people’s perspectives, coping, children

Introduction
The concepts of ‘coping’ and ‘coping strategies’ are rooted in responses to the famines of the 1970s and 1980s in Africa (De Waal, 1989; Devereux, 1993). With the onset of HIV/AIDS, the language of ‘coping’ has become widely used to indicate the extent to which households and communities have the wherewithal to respond to adversities resulting from the epidemic (UNAIDS, 1999). However, notions of ‘coping’ can under-estimate the stark realities for many households and communities affected by HIV/AIDS, who are in fact ‘struggling’, rather than coping in any positive sense (Rugalema 2000). In addition, the assumption of ‘coping’ may divert policy-makers from the enormity of the emergency that a household or community is facing.

Rather than devising a planned sequence of measures, or ‘coping strategy’, in response to the difficulties faced, households affected by HIV/AIDS often respond to immediate problems in a reactive way, for example by selling off assets to meet their immediate needs (Donahue 1998, National Agricultural Advisory Service of Uganda 2003). Other responses include intra-household labour re-allocation, taking children out of school, making use of fewer crop varieties or less labour-intensive crops, reducing the area of cultivation and/or the size of livestock herds, and reducing the quality of food and its frequency of consumption (UNAIDS 1999, National Agricultural Advisory Service of Uganda 2003). While traditional community-based support networks enable reciprocal arrangements to alleviate hardship, these are increasingly struggling to respond adequately, given the scale of the epidemic (Family Health International, 2003) and may not always be equitably applied (Baylies, 2002).

Research now demonstrates that the poorer the household, the more likely it is that the measures adopted will prevent longer-term recovery of the household economy (Skoufias, 2003). Eventually, many households reach a point where they have no further coping mechanisms to employ and are either dissolved or fail to ever regain the quality of livelihoods that they had prior to the death of a prime-age adult (Donahue 1998, Seeley 1993, Yamano et al 2002).

The literature relating to how individuals and in particular children cope in response to the complex and difficult circumstances posed by HIV/AIDS - usually in combination with other adversities - is limited (Mann 200, FHI 2003, Save the
Children 2002). For children affected by HIV/AIDS, coping can be observed at two levels: coping in relation to meeting material needs and basic commodities; and coping on an emotional level, part of what has come to be termed the ‘psychosocial’ aspects of responding to illness and death (Stein, 2003).

Some previous work has explored the notion of resilience and how it can be nurtured in children affected by HIV/AIDS (Mallmann, 2002). Resilience has been defined as ‘the human capacity to face, overcome and be strengthened by or even transformed by the adversities of life’ (Grotberg, 1995) or the ability to ‘bounce back’ after stressful or traumatising events. Building resilience has the potential therefore for both protecting children from different forms of vulnerability resulting from the death of parents or relatives, and enhancing their ability to cope.

**Overview of material and methods**

This paper describes the findings from research conducted in January 2004 for an international non-governmental organisation, Catholic Relief Services (CRS), across six sites in Zimbabwe. The aims of the study were to provide a view of the daily lives of children and young people between the ages of 8 and 18 years affected by HIV/AIDS; ascertain children and young people’s perspectives on their needs and document the coping strategies used by them in relation to specific challenges; illuminate their support networks; analyse the effects gender and age have on children’s ability to cope; and identify key adults’ perspectives on orphans’ lives, needs and coping strategies.

The six sites were chosen by CRS both to reflect a cross-section of settlement types in Zimbabwe, and for logistical reasons, in particular the location of partner organisations. Two sites were urban (Harare and Bulawayo), three were in rural communal areas (Chegutu, Chinoyi and Rusape) and one, a formerly predominantly commercial farming area, (Mazowe). Local teams of researchers were trained by the authors in data collection and analysis, and were responsible for conducting the case studies and interviews in each site.

Case studies formed the central research tool due to their potential to provide particularly in-depth insights into the circumstances of a family or household. In each site, three case studies based on in-depth interviews and observations were developed in households where children were affected by HIV/AIDS in varying ways. Case studies provided information on family composition; everyday lives; survival
strategies and sources of support; roles and responsibilities of different family members; experiences of illness and bereavement in the family; views of childhood and child labour; and particular challenges faced by orphans. Semi-structured interviews held with other key informants within communities provided broader insights into the situations of orphans and vulnerable children and the ways in which they coped with the difficult circumstances that they faced. Interviews were conducted in Shona or Ndebele (in Bulawayo), tape-recorded with the permission of informants, and transcribed into English.

A thematic analysis was conducted of interview transcripts and field diaries. Inevitably for a fairly focused and rapid study, emergent themes closely reflected the scope of enquiry. Codes were then set up, coding carried out and data brought together within these key themes.

Ethical considerations of relevance to research with children have been well documented (see for example, Alderson & Morrow 2004), and were extensively discussed during the training of fieldworkers. These included the importance of confidentiality, non-judgmentalism, respect for the right to refuse to participate in the research or to withdraw from the research without explanation, the maintenance of privacy during conversations, and non-disclosure of information to other household members.

Research participants: background information

Table 1, below, provides a breakdown of the research participants in each site. Participants interviewed are broken down into three groups: children under the age of 18; young adults who have assumed adult responsibilities of carers; and adults who were interviewed about their perspectives on the lives of orphans and vulnerable children. The ages of children and young people are listed in brackets; the letters ‘HH’ after a participant indicate that the child or young person was the head of the household.
Table 1: Breakdown of research participants

<table>
<thead>
<tr>
<th>Location</th>
<th>Male children (ages in brackets)</th>
<th>Female Children (ages in brackets)</th>
<th>Young adult male (ages in brackets)</th>
<th>Young adult female (ages in brackets)</th>
<th>Male adult</th>
<th>Female adult</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chegutu</td>
<td>2 (18; 18HH)</td>
<td>3 (15;14;13)</td>
<td>1 (19)</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Mazowe</td>
<td>5 (16;16;16;18;11)</td>
<td>4 (12;15;17;18)</td>
<td>1 (20HH)</td>
<td>1 (26 HH)</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Harare</td>
<td>6 (10;10;12;12;15;16)</td>
<td>8 (7;8;10;12;14;15;15;18)</td>
<td>2 (19; 19)</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Rusape</td>
<td>5 (12;17(HH);10;14;14)</td>
<td>3 (15; 17(HH); 17)</td>
<td></td>
<td>2</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Bulawayo</td>
<td>1 (18)</td>
<td>4 (12; 14;18;17)</td>
<td>2 (19 HH;19)</td>
<td>1 (22 HH)</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Chinoyi</td>
<td>3 (11;14;16)</td>
<td>4 (12;13;14;18)</td>
<td>0</td>
<td>1 (20 HH)</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>TOTALS</td>
<td>22</td>
<td>26</td>
<td>6</td>
<td>3</td>
<td>6</td>
<td>34</td>
</tr>
</tbody>
</table>
Findings

Circumstances of children and young people

Economic hardship was described in every household visited throughout the research, and children and young people of all ages mentioned material difficulties relating to access to food, school fees, soap, blankets, bus fares, clothes and shoes. ‘We go to sleep on empty stomachs, commented one girl aged 15 years. She described how having no food in the house was even more of a problem ‘because mum needs food to take her medication’. A nine year-old boy said ‘I last ate sadza two days ago’ and another 12 year-old boy stated ‘sometimes we eat, sometimes we don’t’.

Many children described not only difficulties in securing basic commodities for themselves, but also the impact the lack of these had on being able to care for others. A 12 year-old girl in Chinhoyi talked about the difficulties of nursing her sick mother alone until her death, and there was ‘no food to eat or soap to clean her wounds’. Similarly, a 14 year-old boy in Chegutu, who was caring for his dying father explained that blankets would help a great deal in his situation. There were only three in the household to share between himself, his father and younger brother. His father needed the blankets ‘because of his illness’. The boy described how he and his brother used old clothes to cover themselves at night.

A lack of food coupled with the absence of adults in the household to secure it meant that this burden fell on even very young children. A 10 year-old boy, cared for with five other children by his sick grandmother in Rusape described how because of his grandmother’s incapacity, the burden of work fell on the children. He talked about how strenuous the work was, often starting at 5.00 a.m., and said that he never had time to play. A 14 year-old girl in Chegutu living with her maternal grandmother and younger sister drew pictures of working in the field. Although she said that the three of them worked together in the field, in the course of the conversation it transpired that her grandmother was usually too sick to help, and her sister, unlike herself, attended school. This meant that most of the time she worked alone to plough and weed the plot of land on which they were dependent for food.

In many cases, older children and young people shouldered the burden of responsibility for providing enough for younger siblings. When parents died, support from other relatives such as paternal or maternal relatives provided some reprieve,
although many children and young people described how the support itself came to an end if this relative also died, became unwell or had other commitments to fulfil, such as assuming the care of other orphans within their families. Households where children seemed to have enough to eat and could be said to be coping usually described some form of extended family support that was helping to sustain the household.

Yet, children and young people identified other needs as well as access to food and commodities. A significant number described the level of abuse and maltreatment that they had experienced from extended family members who had taken them in, and how they felt they were a burden on households. Children described episodes of physical, verbal and sexual abuse throughout the study. Several children also described how, following the death of their parents, property which they should have inherited was taken by other family members.

Coping at household and community level
The study identified examples of community support and strong reciprocal arrangements between households. Some children and young people described how people within the community shared resources, such as land and cattle for ploughing or helped them with food and basic commodities. For every negative response by a community to their situation, described by children and young people, there was a positive response described elsewhere. While for example, some children said they were laughed at by others or taunted about the death of parents or the poverty that they faced, others said that they did not face stigma or bad treatment. Similarly, although some people interviewed felt that the level of support provided to vulnerable children and their families by communities was commensurate with what was available - ‘there isn’t much help in the community in terms of helping each other when hunger strikes’ - there were several examples described where it was the poorest in the community that became volunteers and helped others.

Some collective community responses, however, had a routinely negative impact on children and young people. In Rusape, for example, a home-based care worker talked about how the community was working hard to bring back and promote virginity testing in an effort to prevent the spread of HIV infection. In Bulawayo, young people who chaired the local youth AIDS organisation described how vulnerable children were migrating to South Africa to try and find work. They were
paying money to intermediaries in the hope that they would cross the border and be able to work, only to find that they were usually deported.

More generally, the continuing secrecy surrounding AIDS was perhaps indicative of how communities were not coping with the presence of HIV/AIDS as a whole, although there were rare exceptions where adults were open about their HIV status to their immediate family members. Attributing HIV/AIDS to witchcraft was frequently described as a coping mechanism. People described visiting traditional and apostolic healers in an effort to either seek a traditional cure for illness or an antidote to being subjected to witchcraft. This type of culturally embedded response has been documented elsewhere (e.g. Bond et al, 2002). While in some ways attributions of witchcraft might potentially reduce the stigma associated with HIV/AIDS-related illness, in other ways they created family conflict and mistrust and reflected a collective denial of the existence of HIV/AIDS. A young woman, aged 18, in Bulawayo commented on the negative impact on children when adults pretended that parents had died because of witchcraft:

‘Witchcraft is perverting the mind of the child. It is better at least to say your mum had a long illness, if you don’t want to say anything. When my mum died I was 15 and she [relative] should have told me – I would have accepted that she died of AIDS’

Children and young people often had little control over the types of coping strategies employed by their elders, even though these ultimately affected them deeply and at times in negative ways. One 12 year-old boy was forced to leave school and home by paternal relatives and care for his terminally ill father; a young girl of 13 years was dissuaded through threats to her life from disclosing the fact that she had been raped by her uncle, because of the impact this would have on access to household resources; some children described how they had just been left by relatives one day because they (the relatives) were no longer able to cope themselves; and an 8 year-old girl in Harare described how she could not always attend school because she often had to take care of her baby sister. All these could be defined as coping mechanisms which children and young people were powerless to question.

Adults assumed many practical coping mechanisms to meet basic needs, all of which impacted in some way on the lives of children and young people. These
included activities into which children and young people were also drawn such as selling surplus from subsistence farming, working on other people’s land (weeding or harvesting) in return for food or money, and cross-border trading. Other strategies had potentially more negative long-term effects on household security and included selling livestock such as chicken or cattle, and selling household possessions including electrical goods or furniture. Where there was inadequate income, families repeatedly described taking more stringent measures, such as reducing the number and quality of meals eaten and withdrawing children from school. A further strategy employed by adults in urban areas was to reduce their living accommodation and rent out rooms to others. As a result, several children described living in cramped conditions. Adults also described moving either to town from rural areas, in an effort to reduce the pressures of rural work-load, or from town to rural areas where goods were considered cheaper and they could eke out a subsistence-level of survival. Children described (sometimes multiple) moves between different environments over which they had no say or control.

Adults’ perceptions of how children cope
At a practical level, children’s coping strategies fall into two main categories: diminishing needs; and generating supplementary income (Save the Children, 2002). Overall, adults interviewed pointed to the fact that children facing hardship were usually orphans, though not exclusively so – some children with parents were said to face similar hardships. Adults described multiple activities carried out by children to cope with the lack of daily food and basic commodities, including working in other people’s fields; herding other people’s cattle; running stalls in the market; selling vegetables; working on buses and other small-scale activities.

Negative incidents of coping by children and young people were also identified by adults, such as stealing and gambling, although they rarely equated this with ‘externalised’ distress, complaining instead that some young people were out of control. In one research site, reference was made to children being involved in gold-panning which had led them to drop out of school. Many references were made to the sexual behaviour of young people, and concerns were raised about them putting themselves at risk from HIV/AIDS. Early marriage was also widely viewed as something that was increasingly prevalent in communities. While some in the community saw early marriage as a necessary response to pregnancy, brought about
through the breakdown of traditional norms and moral codes, others felt that marriage was either something young people, especially young women, were forced into since families could no longer take care of their children, or it was seen as a means of escape and a way of alleviating their situations.

In Bulawayo more than in other sites, adults working with children, for example as counsellors, discussed the psychological and emotional needs of children and young people and the extent of cumulative grief faced by many children who had experienced the death of several family members. One counsellor talked about the initiative and resilience of children that can be encouraged, once their grief is acknowledged:

‘Once they accept the future and people accept them and their problems, they get strength and go back to school or become peer educators….their talents need to be identified’.

Children’s views on coping
Children and young people who were orphans and helped by their extended family described situations in which they felt significantly better off than other children with no such support (Wild, 2001). A 12 year-old boy in Bulawayo whose father had died talked about the emotional importance to him of the regular visits from his maternal uncle. His paternal uncle also visited regularly and paid his school fees if his mother had not managed to do so. Others described the significance of visits from family members, an indication that they were cared for and not forgotten. There were also several examples of extended family living far away paying someone locally to take care of children, or sending money or clothes whenever they were able. Others, however, described the presence of extended family that never gave them support. This was often put down to their inability to do so. As a 17 year-old boy heading a household in Rusape commented: ‘relatives do not help us, they do not have the resources’.

For the most part, children (like adults) focused on the practical coping mechanisms that they employed and described day-to-day activities that were carried out in order to sustain themselves and their household, rather than on how they coped psychologically and emotionally. Children of all ages described their roles within
their families, although the expectations on younger children varied. While in some households they took on significant responsibility to contribute to the household chores and economy, in others they seemed to retain more of their status as children.

Children were clearly adept at drawing on wider resources within the community and those as young as 12 described ways in which they sought assistance from others through asking for vegetable seedlings to grow their own vegetables or borrowing food or money from neighbours when hungry - paying it back when they had surplus or when they were given handouts by NGOs. A 12 year-old boy in Bulawayo talked about how he would mould bricks and sell them, as well as sell vegetables and fruit to get money for food or exchange them for treatment at the local clinic if he was sick. Other strategies adopted by young people were more subtle, such as doing whatever they could to ‘please’ relatives who had taken them in. A 14 year-old boy in Rusape described how he did his allocated tasks without complaint in an effort to ‘try to make my grandparents happy about keeping me’.

A wide range of strategies to help secure their basic needs were described by children and young people. These included fishing in the river; selling or exchanging whatever resources were available, such as mangos and frozen drinks; working in other people’s fields; herding others’ cattle; washing or looking after cars; moulding and selling bricks; roasting and selling mice; bee-keeping; recycling plastic bottles; and many others. On the whole, these activities were carried out to secure the basic minimum needs of children and their siblings, and in many cases their survival depended on these activities. However, young people felt that they were not always treated fairly by those they worked for. A 14 year-old girl in Chegutu said,

‘People in the village are very difficult because you weed the whole day and they give you no food and re-negotiate the money that was agreed. When you have done all the work …then they will only give you $8,000 instead of 10,000’.

Importantly, boys described a wider range of potential income- or resource-generating activities than girls. While boys talked of fishing, hunting, brick-making, carpentry, herding others’ cattle, and so on, the economic activities described by girls were more confined to working in other people’s fields and selling vegetables from
gardens, or asking neighbours for help in the form of food or soap or other basic commodities.

Psychological and emotional coping

Children and young people frequently described the death of more than one parent or relative. The death of a mother was often felt by adults and children alike to be particularly significant because they (mothers) were more likely to provide care and security for a child. Several respondents described how their lives were drastically changed as a result of losing their mothers. A 10 year-old boy in Rusape said,

‘When I heard that my mother had died, I was out herding cattle. I felt weak and fell unconscious only to gain consciousness when I had been taken home. The thought that I would never see my mother again saddened me and then my father also passed away. There I was with no parents’

Children reported various ways in which they sought to relieve the strain of the difficulties they faced. As in other studies (e.g. Mann 2002, FHI 2003), talking to friends rather than to adults was a common support-seeking strategy. For younger children up to the age of about 12 years, meeting up with friends, playing games and talking to older siblings were strategies they employed. An 11 year-old boy in Chinhoyi described how he told his older sister his problems and asked her to tell him fairy-tales. An 11 year-old girl in Chegutu talked about how her friend ‘tells me funny stories and releases my stress’. Two girls aged 7 and 10 years, interviewed together, talked about the games they played, and the enjoyment they derived from attending school.

For some children in this younger age group, coping also came through a sense of acceptance of their ‘lot’. While for some this came across as resignation and low expectations, others demonstrated a great deal of resilience and hope for the future. An 8 year-old girl in Harare who had been subjected to severe physical and sexual abuse, for example, commented that ‘life will always be like this’. Another 10 year-old boy described a situation at home where he was treated badly, shouted at and not given enough to eat; he seemed resigned to the situation.

While some older children, particularly girls, employed similar emotional strategies as younger children such as ‘sharing problems with friends’ or collecting
firewood with friends so that they can ‘discuss things’, others said that they did not tell anyone their problems. As children grew older, it appeared that they could make fewer demands for emotional support and the demands on them to provide emotional support to others increased. A 15 year-old girl in Chegutu commented ‘I still need to be cared for myself’, even though much of her time was spent taking care of her sick mother. Several young women of 14 years and above described the caring responsibilities they had for sick parents and relatives while simultaneously taking care of younger siblings. The emotional as well as physical demands on them were clearly visible.

Children and young people who were heads of households often displayed great resilience, despite being forced to deal with multiple difficulties at once. A 17 year-old young man, head of a household in Rusape, listed numerous strategies he employed to look after himself and his younger sister and sustain the household. He commented, ‘I make decisions for the young ones and make sure they go to school – I am taking care [of them]’. When asked about how he coped with the difficulties he faced, he responded ‘I always find solutions’. Similarly, an 18 year-old boy in Chegutu who ran his household with sporadic help from his older brother’s wife, and who described himself as the breadwinner, described how he grew ground nuts and fruit to sell and worked in other people’s fields to get money. When asked how he found his situation, he replied ‘I don’t have any problems’. The degree of resilience and resourcefulness demonstrated by these young people is important since there is a risk of categorising children in specific circumstances as all being equally vulnerable. In reality, some young people may be coping better than others in practical and/or emotional ways. Understanding the opportunities and constraints of each individual young person’s circumstances is key to providing them with the most appropriate support, be it economic, practical, emotional, or a combination of these.

**Negative coping strategies**

Examples of more negative ‘coping’ strategies from children and young people’s narratives included life-changing strategies such as going to live on the streets; moving from place to place until they found some level of security; leaving home and getting married with the hope of improving their life situations. One young woman in Harare aged 18 had been forced (at the age of 17 years) to leave her job as a domestic worker since she had no identification papers. Left destitute she commented, ‘my only
way out was to get married’ and described how she met and married her husband within two months. Other strategies included reducing the number and size of meals eaten, and - in the case of young people living on the streets - searching for food in rubbish bins, or exchanging sex for food or shelter (Rurevo and Bourdillion 2003, UNICEF 2003a).

Leaving school early has increasingly been documented as a strategy adopted in order to relieve difficulties at home (UNICEF, 2003b). Despite the evident emotional as well as learning benefits awarded through attending school, a significant proportion of children and young people interviewed were not attending school; those living with extended family members rather than their own parents were less likely to be attending. Although a lack of school fees or money for books and uniform were the most commonly cited reasons for withdrawing from school, some children, especially girls, described caring responsibilities that prevented them from attending.

Discussion
Given that this research took place during a time of particular economic and seasonal hardship in Zimbabwe, the primary needs identified by children and young people were essentially basic material needs: having enough food to eat, as well as clothes and shoes, blankets, soap to stay clean and healthy, school uniforms and equipment, and money for school fees. Most were experiencing extensive poverty and in some cases suffered stigmatisation, frequently as a result of poverty combined with the association made by others with HIV/AIDS, following a family member’s serious illness or death. Beyond these needs, a significant number of children and young people were subjected to, at times severe, abuse and maltreatment as a result of the reduced protection afforded by strong family networks.

Findings confirmed the fact that children and young people viewed life differently to adults and had different accounts of their own actions and those of others. While adults perceived their behaviour such as stealing as indicative of a decline in values and respect, young people themselves claimed to steal as a means of alleviating hunger. While neighbours of a child headed household claimed to provide help and support, the young man heading the household described how they constantly exploited their situation through stealing fruit from their trees, letting cattle wander onto land and crops, not giving a fair price for the fish that he caught, overcharging him for fertilisers, and failing to assist him in any way with animals to plough with.
Other young people also repeatedly described the lack of respect given to them even though they were expected to assume the responsibilities of adults more so than ever before (UNICEF, 2001).

Similarly, where children and young people may be perceived as coping well following the death of a parent or other family member because they become quiet or withdrawn, some young people described how they felt angry, upset and often excluded from opportunities to grieve and come to terms with their loss, for example by attending funerals or visiting the graves of relatives.

This study and others (see, for example, Giese et al, 2004) have highlighted the fact that many children and young people face considerable vulnerability before the loss of a parent and the point at which they are considered to be orphans. The study revealed that in current times, children are more likely than ever to be expected to assume the responsibilities of care for sick relatives or younger siblings and of providing sources of income or food, rather than sharing these responsibilities with adults as part of a household unit. Young women in particular described burdens of caring practically and emotionally for terminally ill adults which most adults would find overwhelming. While on the surface they ‘coped’, the toll that it had on their mental health and well-being was evident in their often highly emotional responses to the research process.

The research has illustrated the importance of engaging children and young people more centrally in the process of identifying household and community needs and in responding appropriately. Yet, by positioning the views and perspectives of children more centrally in programme responses, agencies potentially meet a major stumbling block. How are children’s rights construed within local communities? and where do the individual rights of the child fit with children’s obligations and responsibilities in the collective view of family and community? These are issues that organisations at a national and local level need to grapple with.

Despite the scale of loss experienced by many of the young people in this study, there were very limited services providing any direct psychological support to children and young people who had experienced such loss (Giese et al 2004, Germann 2004, UNICEF/UNAIDS 2004). The exceptions were two informants who had attended Masiye camp (Horizons, 2005) (and spoke highly of the experience). Teenagers, especially, described participating in the everyday care of the sick, yet were rarely told what was happening, given a chance to express their feelings or be
involved in decision-making. One key finding from the research was that adults themselves - whether the sick parent, other relatives in the household or a care-giver following parental loss - are often ill-equipped to identify and manage children’s distress positively. Children who internalised their feelings and became withdrawn were perceived by adults to be coping and similarly, adults appeared to misinterpret signs of distress as ‘difficult’ behaviour (Sengendo & Nambi, 1997).

During the course of the study, it became evident that many of the effects of HIV/AIDS were strongly gendered. Girls were most likely to assume the role of carers of sick relatives or siblings, once their own care-givers had become incapacitated through illness. As a result, they most often had to give up their education. When the male head of household died, their wives were often subjected to property-grabbing by in-laws, with implications for their children. Furthermore, the effects of loss also appeared to be gendered. A number of research participants described how the emotional outcomes for children and young people were worse when a mother died than when a father died. One adult participant described how she felt that the maternal bonds were much stronger and that paternal relatives were always in a position to claim that children were not those of their deceased male relative. In some cases, this approach led both to the abdication of responsibility on the part of paternal relatives, and added to the stigma of the surviving wife and her children.

Conclusions
This research has clearly shown the distinct and unique perspectives that children and young people affected by HIV/AIDS have on their lives and the importance of incorporating these views in HIV/AIDS programming. Many demonstrated considerable resourcefulness, but required further guidance and support in order to make their livelihoods more sustainable and to alleviate some of the burden of care put upon them. Young people as well as those categorised as children are equally in need of support since they have assumed responsibility for the care of others, often from a young age, but are not awarded the status or recognition as adults. The psychosocial impact of HIV/AIDS on children and their families demands much closer attention, and a greater understanding needs to be developed of their capacity to cope emotionally with grief and loss, and how best to respond to these needs. Adopting a more holistic understanding of children and young people’s capacity to
cope - on emotional as well as practical levels - is vital if future programming is to respond more effectively to their needs and allow them to build resilience, enhance their resourcefulness and be able to live up to the huge expectations that are placed upon them.

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