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Hidden Young Carers: the Experiences, Needs and Resilience of
Children Caring for Parents and Relatives with HIV/AIDS in Tanzania
and the United Kingdom, 2006

USER GUIDE

**ESRC project Hidden Young Carers: The Experiences, Needs and Resilience of
Children Caring for Parents and Relatives with HIV/AIDS
Prof. Saul Becker and Dr. Ruth Evans**

Research design

Methodology

This research has been developed from a sociology of childhood perspective, which recognises that children are not passive recipients of social structures and processes (James and Prout, 1997), but rather are social actors who consciously make choices about caring or who are drawn into caring through ‘pushes and pulls’ which often combine relational, familial, socio-cultural and structural elements. A child-focused methodology both acknowledges children’s agency in the construction of their social lives and caring roles and the social determinants which influence these.

Methods

Given the hidden situation of young carers within families affected by HIV/AIDS, qualitative methods are considered most appropriate to gain an in-depth understanding of the perspectives and experiences of this group of children, their families and key professionals in contact with them. Participatory methods which focus on ‘task-centred activities’ are often advocated by childhood researchers as effective in engaging children in research and enabling them to express their ideas and opinions (Christensen and James, 2000). Thus, in addition to tape-recorded semi-structured interviews with children, parents/relatives and professionals, a range of other participatory methods will be used to engage children, depending on age and levels of literacy including: drawings, map-making, poster-making, written diaries or stories, and sentence completion exercises, which Dr. Evans has used in her previous research (Evans, 2004; Hill, 1997). Interviews with children and parents/relatives will be conducted at the pace and in the direction that children and parents/relatives wish.

Themes which will be explored with children and parents/relatives include:

- family background (age, gender, ethnicity, family structure);
- caring biography (period of care, number of hours per week, circumstances leading to care, why their responsibility);
- protective factors, coping strategies, social ties, social networks, caring identities and relationships in the family/home, school, community;
- informal/family support;
- formal/professional support;
- needs and aspirations.

Themes explored in interviews with professionals include:

- definitions of children affected by HIV/AIDS and young carers;
- perceptions of positive/negative experiences and outcomes/impacts of children’s caring roles in HIV/AIDS-affected families;
- similarities/differences between the experiences of this group and those of other young carers;
- needs and requirements for support of young carers and their families;
- services currently available for young carers/children and families affected by HIV/AIDS and factors influencing take-up (e.g. stigma);
- professional approaches to the issue of young caring;

- practices which enhance children and families' resilience and strengths;
- roles of statutory, voluntary, community and informal caring sectors in meeting the needs of young carers.

More than one visit to children and their families is likely to be necessary for data collection purposes, because of the sensitive nature of the interviews and the need to build a degree of trust in the research relationship. Interviews will be conducted in participants' preferred language, using a translator if required in the UK. Dr. Evans has a good level of spoken Kiswahili, the national language of Tanzania, and extensive experience of conducting interviews in Kiswahili while living in Tanzania for extended periods.

Sample and location

Investigators will identify a sample of children in each country aged under 18 who care for parents/relatives with HIV/AIDS or those who are orphaned but previously cared for parents with HIV/AIDS. In the event of difficulties in accessing this group due to the stigma and their invisibility, the sample could also include young adults aged 18-24 who continue to care for parents/relatives with HIV/AIDS or who cared when they were younger. This approach to selection has been used in several young carers studies where accessing children has been particularly difficult (Dearden and Becker, 2000; Frank *et al.* 1999). Children's parents/relatives will also be interviewed, including where appropriate those with HIV/AIDS and receiving care. Young carers will only be selected to participate where HIV/AIDS has been recognised, either medically or by organisations working with family members. The views of professionals working directly with participants will be sought, and the 'key workers' working with individual families will be identified by families themselves (Aldridge and Becker, 2003). In addition, or in the absence of a 'key worker', key professionals working at a strategic/policy level locally and nationally will be interviewed.

The investigators will draw on their links with voluntary and community organisations working with young carers and children affected by HIV/AIDS in Tanzania and the UK to gain access to participants. In Tanzania, families will be accessed in the Dar es Salaam and Arusha/ Kilimanjaro regions, where the Co-investigator has good contacts with local organisations working with families affected by HIV/AIDS. The investigators will conduct fieldwork with Tanzanian young carers and their families first, in order to learn about their resilience, coping strategies and protective factors within a context of high HIV prevalence and limited state welfare support. This insight into Tanzanian young carers' resilience will be a useful starting point for the UK fieldwork. It is anticipated that in the UK, families will be located in large urban areas where it is known that larger proportions of the population are affected by HIV/AIDS.

Ethical issues

The researchers recognise adult-child power differentials and will seek to put participants at as much ease as possible. Respect for privacy, confidentiality and rights to anonymity are paramount, as is the safety and security of the researchers and research participants (see Becker and Bryman, 2004). Written outputs and the dissemination strategy will ensure participants' anonymity, including when direct quotations or descriptions of family circumstances are provided. Informed consent

will be required of all participants (both adults and children) and will be secured through the following means:

- An accessible leaflet designed for children and parents/relatives giving information about the research project in appropriate languages will be given to potential participants prior to meeting them.
- Parents/relatives and children will each be asked for consent in their own right, although where interviews are to be conducted with children under 16, parents/next of kin will be required to give additional written consent.
- Children will only be invited to participate in the study if they are aware of their parents/relatives' HIV status, to ensure that consent to participate is fully informed.

We are committed to interview only children and parents/relatives who are aware of their HIV status and willing to speak to the researcher about their caring relationships. Because this may cause difficulties in recruiting a full sample, we may include younger adult carers (aged 18-24) who have cared or continue to care for a parent/relative with HIV/AIDS.

Consent will be continually renegotiated at each session and participants' right to withdraw at any time will be emphasised. If the child wishes, their parents/relatives may remain present throughout interviews. Additionally, participants may switch the tape-recorder off if they do not wish aspects of the conversation to be recorded and the researcher will make detailed field notes during or immediately after the interview. The researchers recognise that revisits may be necessary if a child becomes distressed or does not wish to continue with the interview in one session (Robson, 2001). Following the final session, information will be offered to children and families about accessing support services from local organisations where available. In line with current social research practice, vouchers (in the UK) or a financial payment (in Tanzania) will be offered to all children and parents/relatives participating in the study to compensate for their time and participation in the research process.

This research complies with the requirements of the Research Governance Framework for Health and Social Care and the ESRC Research Ethics Framework and conforms to the ethical protocols of the Social Research Association and British Sociological Association. The proposal and research design and methods have been approved by the Research Governance Officer of the University of Birmingham, the Research Support Office and the Director of Research for the School of Social Sciences at the University of Birmingham. They have also been scrutinised by the Institute of Applied Social Studies current system for ethical clearance. Independent ethical approval will be required from the National Institute of Medical Research, Dar es Salaam, who will be approached if this proposal is successful (contacts have been made and problems are not anticipated). Interview schedules and all written material developed for the project will be subjected to the University systems as identified above, and will be scrutinised by the project's Research Advisory Group, which will have an on-going role relating to issues of ethics, harm, risk etc. Dr. Evans has been police-checked (Standard Disclosure) by the Criminal Records Bureau in 2003. Prof. Becker and Dr. Evans have no conflicts of interest (personal, academic or commercial) in conducting this research.

Data collected for the project

The child-focused methodology and use of qualitative and participatory methods enabled us to gain an in-depth insight into the experiences of children, parents and guardians and professionals supporting the families. Access to children and parents who met the research criteria was negotiated with non-governmental organisations supporting the families in Tanzania and the UK. Semi-structured interviews were conducted with children and parents in their homes or at the non-governmental organisation that supported them.

Some of the children completed a 'My Story' book designed for the project (in English or Kiswahili) in their own time to assist in gaining a more in-depth understanding of their caring responsibilities and social worlds. The book included sentence completion exercises and spaces for drawing or collage. Digital photographs were taken of completed pages of the book so that children could keep their books. Children were also given disposable cameras to take pictures of people and places that were important to them and to show their everyday experiences of care work. As part of the interview, children were asked to explain their photographs to the researcher and were given a copy of their photographs to keep. Group discussions were also conducted in Tanzania with two groups of young adults living with HIV.

Tape-recorded semi-structured interviews were conducted with a total of 93 respondents in Tanzania and the UK.

Research conducted in Tanzania

- 22 children and young people caring for a parent/relative with HIV/AIDS or who used to care for a parent with HIV (aged 11-24)
- 21 mothers or female relatives with HIV or guardians of orphaned children
- 13 service providers from non-governmental organisations supporting children and families affected by HIV/AIDS
- 2 group discussions with young adults with HIV (aged 24-30)

Research conducted in the UK

- 11 children and young people caring for a parent/relative with HIV/AIDS (aged 9-19)
- 12 mothers with HIV
- 14 service providers from voluntary and community sector organisations supporting children and families affected by HIV/AIDS.

Interviews were conducted in rural and urban locations in four regions of Tanzania (Dar es Salaam, Arusha, Manyara, Kilimanjaro) and in five urban areas in the UK (within Greater London, the South East, East and West Midlands).

Record of data to be archived with ESDS

93 transcripts were produced from 91 tape-recorded interviews and two interviews which were not recorded (extensive notes were taken during the interview which were subsequently written up in the form of a transcript). The Tanzanian interviews were conducted in Kiswahili, transcribed and translated into English. Digital photographs of life story book pages completed by children are included in the dataset if the pages do not include identifiers. Most of the life story books were completed in Kiswahili by young people interviewed in Tanzania and they were asked to read out what they

had written in their books as part of the interview. The translation of the pages is therefore included in the interview transcript. Four children in Tanzania only completed life story books and these have been translated into English and typed up.

The following table provides an explanation of the transcript codes:

Methods and research respondents	Transcript codes	
	Tanzania	UK
Semi-structured tape-recorded interviews with children and young people currently caring for a parent or relative with HIV or who used to care for a parent with HIV	C1-C22	C23-C33
Pages of life story books completed by children	C1a, C1b etc. (pages completed by child interviewed as C1) CAa, CAb etc., CB, CC, CD (pages completed by children who only did life story book)	C23a, C23b etc. (pages completed by child interviewed as C23)
Semi-structured interviews with parents/relative with HIV or guardians	P1-P21	P22-P33
Semi-structured interviews with service providers and project workers	S1-S13	S14-S27
Group discussions with young people with HIV	Group discussion 1 & 2	

Transcript codes C20 and P21 were not recorded due to a faulty tape recorder, but extensive notes were taken during the interview and written up in the form of an interview transcript.

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Hidden Young Carers:

The Experiences, Needs and Resilience of Children Caring for Parents and Relatives with HIV/AIDS in Tanzania and the UK

Stakeholder Report 2007



Figure 1: 'This picture shows me caring for my mum when she was ill', drawing by Neema (aged 18) who cares for her mother with HIV and three younger siblings.

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Background

Children with caring responsibilities

Children's informal, unpaid care work within the family became a growing concern in the UK throughout the 1990s. The term 'young carer' refers to children who take on a quantity or quality of caring tasks which are often associated with adult responsibilities and which, when conducted by children who are unsupported, can be associated with negative outcomes for their own health, well-being and development (Becker, 2000). Census 2001 figures show that 175,000 young carers live in the UK, although this figure is unlikely to include children caring for parents/relatives with HIV/AIDS (Becker, 2005). While research focuses on young carers in high income countries, the experiences of young carers in low income countries have been largely overlooked. The number of children currently working as unpaid carers is unknown, but many children in sub-Saharan Africa are increasingly likely to have significant caring responsibilities for parents and relatives with HIV/AIDS (Ogden *et al.*, 2004; Robson and Ansell, 2000).

This study has been informed by a number of perspectives. Recent research has recognised that not all young carers experience negative outcomes (Dearden and Becker, 2004) and suggests that a *resilience* perspective may help to explain individual differences in coping with adversity (Newman, 2002a; 2002b; Rutter, 1990; Evans, 2005; Howard *et al.*, 1999). The *ethic of care* draws attention to reciprocal caring relationships, recognising that there is no fixed division of roles between 'care-givers' and 'care-receivers' (Sevenhuisjen, 1998; Tronto, 1993). A *sociology of childhood* perspective recognises that 'childhood' is a historically contingent, socio-cultural construct and acknowledges children's agency in the construction of their social lives as well as the social structures and processes that constrain them (James and Prout, 1997).

Impacts of HIV/AIDS on children and families

By 2010, an estimated 20 million children globally will have lost at least one parent to HIV/AIDS, the majority of whom live in sub-Saharan Africa (UNICEF, 2006). In Tanzania, over one million adults (aged 15-59) were estimated to be living with HIV in 2005, with an overall prevalence rate of seven per cent among adults (TACAIDS *et al.*, 2005; RAWG, 2005). Over 1.1 million children were estimated to be 'most vulnerable' in 2007, that is, over five per cent of the population of children under 18 years (MHSW, 2006). However, only four to six per cent of orphans and vulnerable children receive any external support (*ibid*).

While the HIV/AIDS epidemic in the UK does not match the scale of Tanzania, HIV prevalence has increased rapidly since the late 1990s (THT, 2003). An estimated 63,500 people (aged 15-59) were living with HIV in 2005, two thirds of whom are diagnosed and accessing treatment and care (HPA, 2006). The number of HIV affected children (those living in families where one or more members is HIV infected) in the UK is unknown but has been estimated as between 15,000 to 20,000 (Conway, 2006). The global HIV pandemic continues to adversely affect black and minority ethnic populations, particularly recently arrived African migrants and refugee families, with a majority of heterosexually acquired infections acquired in Africa (68 per cent) (HPA, 2006).

Objectives

The study aimed to explore the similarities and differences in the experiences, needs and resilience of children who care for parents/relatives with HIV/AIDS in Tanzania and the UK.

The key objectives were:

1. To compare and contrast the structural and relational factors which influence whether and why children become carers in Tanzania and the UK.
2. To develop an understanding of the experiences, needs and resilience of children caring for parents/relatives with HIV/AIDS in Tanzania and the UK and to identify similarities and differences between the countries.
3. To begin to identify the policy and practice implications of young carers' experiences, resilience and needs for health, social care, education, voluntary and community sectors in Tanzania and the UK.

Methods

Gaining access to participants

Investigators identified a sample of parents/relatives and children (aged under 18) and young adult carers (aged 18-24) in each country who cared for, or used to care for, parents/relatives with HIV/AIDS. Children and parents/relatives themselves identified the project worker, who had worked most closely with them, to be interviewed, following Aldridge and Becker's (2003) approach. Accessible information leaflets were given to children and parents prior to meeting the researcher. Following negotiation of consent to participate, semi-structured interviews were conducted with children and parents in their homes or at the offices of non-governmental organisations.

Participatory methods

The child-focused methodology and participatory methods enabled the investigators to gain an in-depth insight into children's experiences. A life story book, based on the idea of 'memory books'¹, was designed for the project (in English and Kiswahili) for children to complete in their own time. The book included sentence completion exercises, a diary of a typical day and spaces for drawing or collage (see Figure 2). Digital photographs of completed pages were taken as a record of the data so that children could keep their books. Children were also given disposable cameras to take photographs of people and places that were important to them. Children were asked to explain their photographs and were given a copy to keep. Participatory methods helped children to talk about their caring responsibilities and sometimes painful, life experiences, as well as sometimes providing a distraction if a child became upset during the interview.

Time of day	What I do	How I feel
6:30 am	I get up and help my brother and sister get ready for school	tired
9 am	I get to school and say hi to my friends	happy
4pm	Home time! I'm on the bus going home.	happy
5pm	Help do house work. Might make my mum tea	tired
8pm	Have dinner!	OK!
9pm	Do my coursework	Confused!

Figure 2: 'A typical day' diary page completed by a young carer as part of the life story book

¹ The Memory Book is the central tool used in memory work with parents with HIV and their children which was first developed by the National Community of Women living with HIV/AIDS in Uganda (Healthlink Worldwide, 2006).

Sample and location

Tape-recorded semi-structured interviews were conducted with a total of 93 participants in Tanzania and the UK (see Table 1). We were able to interview almost twice as many interviewees as originally intended (original aim of 48 participants in total). Interviews were conducted in rural and urban locations in four regions of Tanzania (Dar es Salaam, Arusha, Manyara, Kilimanjaro) and in cities/towns in five regions of England (London, the South East, Eastern, West and East Midlands). The qualitative sample cannot be seen as representative of all children with caring responsibilities in families affected by HIV/AIDS across Tanzania and the UK; however, the research offers insights into the hitherto hidden experiences of this group of children and illustrates a diverse range of perspectives.

Most young people in Tanzania and the UK cared for their mother with HIV and sometimes also siblings with HIV in one parent households; the majority were girls. In the UK, most families were African migrants, some with insecure immigration status and two young carers were living with HIV themselves. In Tanzania, some children had lost both parents to AIDS.

Table 1: Number of interviewees

Number of interviewees			
	Tanzania	UK	Total
Young carers (aged 9-17)	15	9	24
• Girls	8	7	15
• Boys	7	2	9
• Presently caring for parent/relative with HIV	14	9	23
• Used to care for parent/relative with HIV	1	0	1
Young adult carers (aged 18-24)	7	2	9
• Young women	6	2	8
• Young men	1	0	1
• Presently caring for parent/relative with HIV	5	2	7
• Used to care for parent/relative with HIV	2	0	2
Parents/ relatives	21	12	33
• Mothers living with HIV	18	12	30
• Female relatives living with HIV	2	0	2
• Guardian	1	0	1
NGO project workers and volunteers	13	14	27
Total respondents	56	37	93

Life story books were completed by a further four orphaned children and group discussions were conducted with young adults with HIV (aged 24-30) and with members of a Most Vulnerable Children village committee in Tanzania. All interviews were transcribed and the Tanzanian interviews were translated into English.

Data analysis

Theoretical concepts such as resilience, the social construction of childhood, gender analysis and ethic of care informed the analysis of the data. Interviews were reviewed to

identify key themes and analytic summaries were written for each interview, which were collated to assist with writing the final report and book.

Ethical issues

Ethical approval was granted by the Social Sciences Research Ethics Committee, University of Birmingham and National Institute for Medical Research, Tanzania. Authorisation for the research was granted by the Tanzania Commission for Science and Technology and the University of Dar es Salaam. The research was informed by the British Sociological Association's and Social Research Association's codes of ethics.

Respect for privacy, confidentiality and rights to anonymity were considered paramount at every stage of the research, as was the safety and security of the researchers and research participants (Becker and Bryman, 2004). Project workers, parents/relatives and children were each asked for consent, with additional written consent from parents/relatives when interviews were conducted with children under 16. Children were only selected if they were aware of their parents/relatives' HIV status. Consent was continually renegotiated at each session and participants' right to withdraw at any time was emphasised. A financial payment was offered to children, parents/relatives and in Tanzania, to NGO workers/volunteers, participating in the study to compensate for their time. Written outputs and the dissemination strategy ensure participants' anonymity.

Findings

Children's everyday experiences of care work

Children performed a range of caring tasks in families affected by HIV/AIDS in the UK and Tanzania, as the table below illustrates, based on children's narratives of their care work:

Table 2: Children's different care tasks in Tanzania and the UK

Care task	Number of children in Tanzania (n=22)	Number of children in the UK (n=11)	Total (n=33)
Household chores	22	11	33
Health care	18	7	25
Personal care	10	5	15
Child care	10	3	13
Income-generation activities	10	1	11
Emotional & practical support	3	5	8

In both countries, all the children had significant, regular responsibilities for household chores, including cooking, cleaning, washing dishes, laundry, shopping; (in Tanzania only) fetching water, tending livestock, cultivating crops and vegetables. Although the household chores performed by children were broadly similar in the two countries, children's care work differs considerably in the intensity and time taken to perform household chores due to disparities in living standards between low and high income countries. In Tanzania, children's care work took longer and was more physically demanding than in the UK (see Figure 3).



Figure 3: 'Here I'm washing the dishes', photograph of Grace² (aged 19) in Tanzania caring for her mother with HIV and four younger siblings, taken by a family member.

Due to the fluctuating nature of HIV illness, children's responsibilities for household chores were interspersed with periods of more intensive care for their parent/relative during episodes of parental ill health or hospitalisation. Most children provided support with their parent/relative's health care, including administering medication; accompanying and providing care while their parent/relative was in hospital; assisting with mobility and preparing special nutritional food for parents/relatives. Half of the children in both countries played an important role in helping their parent/relative to remember to take their anti-retroviral medication at the right time, assisting with adherence to drug regimes.

In the absence of sufficient home-based and palliative care programmes in Tanzania, some children provided intensive nursing and personal care for parents/relatives with HIV at the end of their lives. Children in the UK were less likely to be directly involved in intensive nursing care, due to the universal health care system and provision of hospices and palliative care. However, some children in the UK played important roles in responding to emergencies and assisting parents with mobility and personal care following periods of hospitalisation and serious illness.

Previous research has shown that children's involvement in personal or 'intimate' care is one of the key aspects of their caregiving that most clearly distinguishes the work of young carers from that of other children (Becker, 2007; Robson *et al.*, 2006). Almost half of the children in both countries provided some personal care for their parent/relative. Bathing their parent/relative was the personal care task mentioned most frequently in Tanzania, while children in both countries saw their responsibility for encouraging and assisting their parent/relative to eat as an important priority (see Figure 4).

Although overall there were few disparities between the care tasks boys and girls performed, there was some evidence of a preference for gender matching between the care recipient and caregiver when children provided personal care, confirming the findings of previous research (Becker, 2007; Robson *et al.*, 2006). In Tanzania, a sister or female neighbour was often called on to help bathe/shower a parent, despite a boy's involvement in every other aspect of his mother's care. Similarly, in the UK, parents avoided asking their child to provide personal care if they did not share the same gender. However, there was also evidence that gendered constructions of care were becoming more fluid when households were faced with a lack of alternatives. Almost as many boys

² Young people chose pseudonyms for themselves to be used in written outputs and written consent was sought for the use of specific photographs.

(aged under 18) interviewed in Tanzania were providing care for their mothers/ female relatives as the number of girls, contrasting with the UK sample, and some provided personal care for their mothers, despite the fact that this subverted dominant gender norms.



Figure 4: ‘This is me giving my mum porridge. I feel sad. Here I am giving my mum a shower. These are pictures of me caring for my mum’ (Drawings by Magdalena, aged 15, in Tanzania, who cared for her mother until she died).

Many young people in Tanzania and a quarter of those in the UK assisted their parent in providing childcare for younger children living in the household (usually their siblings and in Tanzania, sometimes orphaned cousins), some of whom were also living with HIV.

Children’s involvement in income-generation activities in Tanzania represented the main difference in children’s care tasks between the two countries. The loss of parents’ income due to increasing ill health meant that almost half of the children in Tanzania regularly took on casual work and engaged in income generation activities to meet the family’s basic needs, including begging, casual farm work, domestic work, selling produce and working in a shop, in addition to their household reproductive tasks.

Many parents are reluctant to disclose their HIV status to their children due to fears about how children will react and the risk of disclosure outside the family (Ely, 2006; Lewis, 2001; Chinouya, 2006). Many children may thus have very little knowledge of the illness of the person they are caring for (Robson *et al.*, 2006). When disclosure takes place, the research found that children were more likely to provide emotional support to their parent/relative, as well as become more involved in performing health and personal care tasks for their parent, due to greater understanding about their illness and greater willingness to care for them. Parents/relatives seemed to highly value the emotional support children provided. Some children in the UK also provided practical support, such as helping parents who experienced memory loss to remember appointments and bills.

Resilience and impacts of children’s care work

Resilience and impacts at the level of the individual child

Emotional wellbeing

Many children said that they liked caring for their parent/relative because they felt that they were helping to make life easier for their parent/relative. Some children in the UK thought that their parent’s illness and caring responsibilities had helped them to become ‘stronger’ emotionally. However, several children in both countries expressed their worry

and anxiety about the life-limiting nature of their parent's illness. Many children were afraid about what would happen when their mother died and parents were concerned about the emotional impact of their illness on their children. In Tanzania, many children whose fathers had died wrote about their feelings of sadness, grief and loneliness. Only a few children who had been bereaved received any counselling or emotional support in dealing with their loss.

Physical health

Over half of the children in Tanzania and some children in the UK described feeling tired or exhausted whilst they performed their caring tasks. Some children mentioned difficulties getting to sleep or other physical symptoms caused by worry and anxiety, while a few sometimes cared for their parent or sibling during the night.

Personal development

Previous research has suggested that children's caring responsibilities can be associated with increased maturity and competencies (Dearden and Becker, 2000; Gates and Lackey, 1998; Hetherington, 1989). This study found that many children thought they had become more mature and independent and had gained greater knowledge and understanding about HIV/AIDS as a result of their caring responsibilities. However, several parents in the UK and most service providers were concerned that younger children were having to 'grow up quicker' and take on 'adult' responsibilities before their time, resulting in a 'loss of childhood'.

Aspirations and priorities for the future

High aspirations have been identified as an important protective factor for children experiencing adversity (Newman, 2002b). Most children in both countries said that continuing their education was their key priority for the future to enable them to have good employment prospects. However, some young people in Tanzania were not able to continue their studies due to their caring responsibilities and the need to earn a livelihood to support their family. In the UK, some young people were worried about how their parent would manage on their own when they moved away to study at university.

Resilience and impacts within the family

Half of the children in Tanzania and the UK commented on their close, loving relationships with their parent with HIV and many thought that their caring responsibilities had helped to bring them closer together. Caring relationships within families were characterised by considerable reciprocity and interdependence, with fluid boundaries between the roles of caregiver and care-receiver. Most children did not identify themselves as a 'carer' but saw their care work as part of their reciprocal responsibilities, love and moral duty towards their family.

Loving, supportive family relationships between children, parents, siblings and other relatives appear to represent important protective factors that help to mitigate children's vulnerability. Extended family relationships were an important source of social support in Tanzania, where formal welfare support is virtually non-existent. However, the resources of extended family members were severely limited and many relatives were unable, or sometimes unwilling, to meet the needs of children and parents in HIV/AIDS-affected households, due to poverty and discrimination. In the UK, only a few children received practical support with their care work from extended family members, as many families did not have access to extended family networks in the

locality or region due to migration, geographical distance, parents' fear of disclosing their HIV status to family members and discrimination.

Resilience and impacts within the school environment

Poor school attendance and academic performance

Most children in Tanzania and the UK reported that they sometimes missed school due to their caring responsibilities, for periods of a few days to up to several months when their parent was seriously ill. Some children mentioned that their caring duties made them late for school, which in Tanzania sometimes resulted in corporal punishment and missing further classes. Almost two thirds of children in Tanzania and a third in the UK thought that their parent's ill health and caring responsibilities had negatively affected their academic performance, finding it difficult to concentrate on their school work due to exhaustion and/or anxiety about their parent's illness. Half of the children in both countries described how their caring responsibilities often conflicted with their time for private study.

Educational resilience and supportive school environments

Despite these negative impacts, over a third of children and most parents in both countries did not think that their parent's illness or their caring responsibilities had any significant effects on their school attendance or academic performance. Most children and parents did not want teachers to know about parent's illness or children's caring responsibilities due to fear of stigmatisation, confirming previous research findings (Cree *et al.*, 2002; Lewis, 2001). Children's resilience, good school attendance and academic performance was related more to informal support from parents, peers and individual teachers, high aspirations, and the child's interests and motivation, rather than supportive institutional environments or sensitivity and awareness of young caregiving among school professionals.

Resilience and impacts within the wider community

Supportive social networks

Most children in both countries mentioned best friends and peers that they enjoyed spending time with and many valued school, college, church, youth clubs, leisure and extra-curricular activities as places of respite from the difficulties they were experiencing at home. Children and parents relied on social networks with neighbours, family friends and members of their faith communities for material support and practical assistance with caregiving.

Conflicts between caring responsibilities and children's engagement in social activities

Almost two thirds of the children in the UK felt that their caring responsibilities restricted their social lives due to conflicts between their caring responsibilities and their own activities. Some children preferred to stay at home, close to their parent, rather than play with their friends and parents were concerned that children's spatial mobility and engagement with their peers was restricted. Some parents also expressed frustration that they did not have more energy to take their children out and do leisure and social activities with them.

Stigma and discrimination

Many women with HIV experienced stigma, discrimination and ostracism from family members, friends, neighbours and others in the community, which was an important factor influencing whether children took on caring responsibilities. Several children in Tanzania also experienced 'stigma by association', including bullying and ostracism from

their siblings, relatives, peers and others, which impacted on their emotional wellbeing and led to social isolation. Although direct experiences of discrimination were not mentioned by children in the UK, the secrecy surrounding HIV significantly affected their ability to talk about their parents' illness and seek support from family, friends, neighbours, school teachers and other professionals.

Formal safety nets and external support

The 17 NGOs involved in the study provided a range of services for children and families affected by HIV/AIDS. However, in both countries, few HIV organisations targeted support specifically to young carers. Free access to anti-retroviral treatment was the only governmental service reported by families in Tanzania, while some children and parents in the UK had mixed experiences of statutory social care services.

Drawing on service providers' perspectives and children's and parents' experiences, it is possible to identify practices and approaches which help to reduce the negative impacts of young caring and build children's and families' resilience:

- Practical, material and emotional support for parents with HIV
- Peer support for parents with HIV
- Holistic family support tailored to the individual needs of children and parents
- Opportunities for leisure, extra-curricular activities and short breaks for children and parents
- Supportive safe places for children to express themselves and develop peer support with others in similar situations
- Opportunities to build life skills, knowledge and understanding about HIV/AIDS
- Building relationships of trust with project workers over time
- Cultural appropriateness, confidentiality and sensitivity to stigma
- Multi-agency collaboration
- Opportunities for participation and engagement in decision-making processes
- Community awareness-raising about HIV/AIDS.

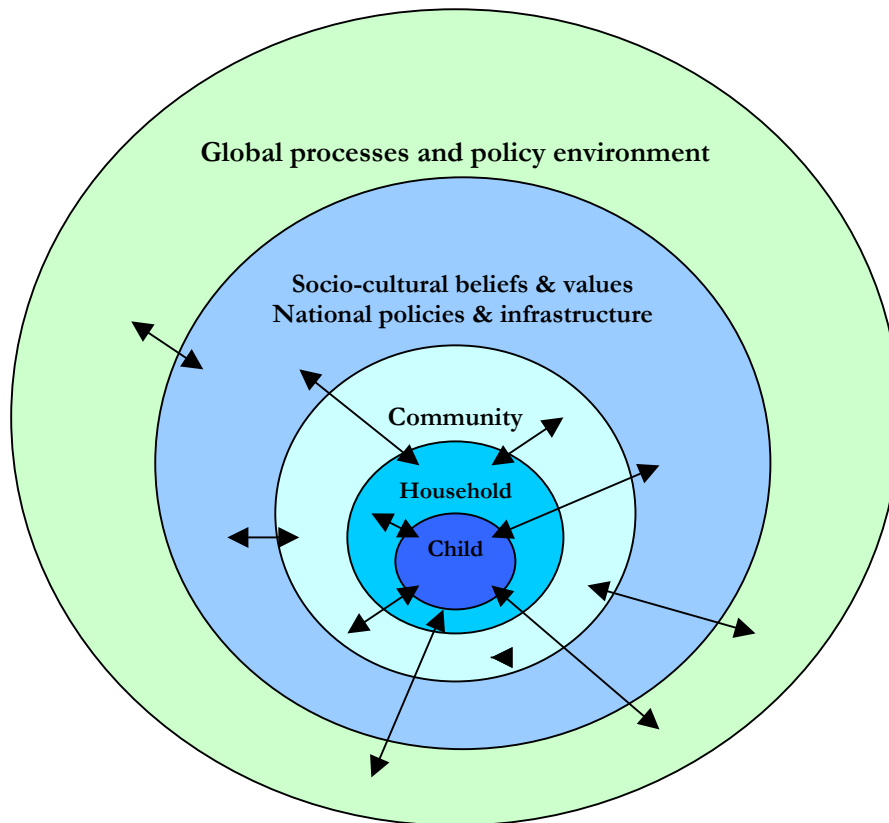
Factors influencing whether children become carers in families affected by HIV/AIDS

Developing Becker *et al.* (1998) framework of 'push and pulls' into young caring, the different factors influencing whether children take on caring roles in families affected by HIV/AIDS can be conceptualised as a nexus comprising the different levels of the individual child, household, community, socio-cultural and national policy context and global processes and policy environment (see Figure 5).

The factors within the nexus represent both risk and protective factors for children living in households affected by HIV/AIDS. At each level, particular factors may play an important role in protecting children from the negative impacts of young caring and limiting the extent of their caring roles; they may also represent potential risk factors, indicating a greater likelihood of children being drawn into caring roles, greater involvement in care work and greater vulnerability to negative impacts of caregiving. For example, extended family support may help to mitigate the impacts of young caregiving and reduce children's involvement, while the absence of such support may increase the likelihood that children take on caring responsibilities, increase the extent of their care work, as well as increase their vulnerability to social isolation.

Figure 5: Nexus of risk and protective factors influencing whether children take on caring roles and the level of their involvement in care work in families affected by HIV/AIDS

<p>Socio-cultural beliefs and values</p> <ul style="list-style-type: none"> • Gender norms and socio-cultural constructions of care • Socio-cultural constructions of childhood • Stigma, knowledge and awareness of HIV/AIDS <p>National policies and infrastructure</p> <ul style="list-style-type: none"> • National legislative frameworks for children & families • National health, social security and social care systems and infrastructure • National AIDS policy • Immigration policies and entitlements • Education policies • Capacity of non-governmental sector • Multi-agency collaboration and coordination of services 	<p>Global processes and policy environment</p> <ul style="list-style-type: none"> • HIV and AIDS pandemic • International migration • Global trade relations and socio-economic position of country in global economy • IMF and WB economic liberalisation policies • International development goals and commitments • International donor aid, programmes and initiatives
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(adapted from Hill and Tisdall, 1997, p.4)

<p>Child</p> <ul style="list-style-type: none"> • Gender, age and sibling birth order • Love, compassion and moral duty • Personal attributes • Co-residence 	<p>Household</p> <ul style="list-style-type: none"> • Parent/relative's health • Parent/relative's disclosure of HIV status to child • Poverty and socio-economic position of household • Changes in family/ household structure 	<p>Community</p> <ul style="list-style-type: none"> • Availability of extended family support • Informal safety nets and social networks among neighbours, friends and peers • Information and access to external support from welfare institutions
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Needs and requirements for support

Children and parents/relatives in Tanzania predominantly saw their needs in terms of financial and material support for their family. Their priorities included: ensuring children's access to education and vocational training; financial and material support to meet the family's basic needs; capital to start a small business; good quality housing; practical assistance for children with household chores and care work; medical care and treatment; nutritional food and paid work to support the family.

Despite a more advanced social welfare infrastructure, many parents and children in the UK also mentioned a need for financial support, struggling to manage on the limited statutory benefits available for low-income families and those seeking asylum. Most children in the UK identified a need for practical assistance with household chores and care work and for opportunities to engage in extra-curricular activities with their peers. Many children in both countries identified a need for 'someone to talk to' and emotional support from project workers. Some children thought that information and training about caring for a person with HIV would help to make their care work easier.

Policy implications

Despite very different socio-economic, cultural and policy contexts, children caring for parents with HIV in Tanzania and the UK share many similarities in terms of their everyday caring responsibilities, needs and aspirations. Informal safety nets and supportive relationships within the family, school and wider community play a significant role in building children and families' resilience and mitigating the negative impacts of young caregiving and HIV/AIDS on households. However, in severely affected communities in Tanzania, as in many other African countries, these informal safety nets are overstretched and the capacity of families and communities to support households affected by HIV/AIDS has been seriously diminished. In the UK and other high income countries, families affected by HIV may not have access to extended family networks or social networks in the community. NGOs and other formal safety nets, however, provide much needed material and emotional resources for children and families, although their capacity to meet the specific needs of young carers and parents with HIV is currently very limited.

There is a need for greater recognition of children's caring responsibilities in families affected by HIV from the local to the global level, and the development of policies, services and support to meet the specific needs of this group of young carers, within the broader category of children affected by HIV/AIDS/ orphans and vulnerable children. Key approaches that promote resilience include practical and emotional support for parents with HIV, holistic family approaches, emotional support for children, opportunities for short breaks, social activities with other young people in similar situations and the development of life skills. The contested nature of the 'young carer' identity and the stigma and secrecy surrounding HIV highlight the importance of cultural appropriateness, confidentiality and sensitivity to complex, diverse needs. Linked to this is a need for greater awareness and knowledge of HIV/AIDS within families, communities, schools, governmental and civil society organisations and welfare institutions. This would reduce stigma and discrimination, enable children and parents to seek support and help to prevent and alleviate children's unpaid care work in families affected by HIV/AIDS.

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The ESRC research report is available on the ESRC Society Today website:

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Hidden Young Carers: The Experiences, Needs and Resilience of Children Caring for Parents and Relatives with HIV/AIDS in Tanzania and the UK Stakeholder Report 2007



Executive Summary



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Context

- Children's informal, unpaid care work within the family became a growing concern in the UK in the 1990s. Census 2001 figures show that 175,000 children have caring responsibilities in the UK, although this figure is unlikely to include children caring for parents/relatives with HIV/AIDS (Becker, 2007). Many children in sub-Saharan Africa are increasingly likely to have significant caring responsibilities for parents and relatives with HIV/AIDS (Ogden *et al.*, 2004; Robson and Ansell, 2000).
- In Tanzania, over one million adults (aged 15-59) were estimated to be living with HIV in 2005, with an overall prevalence rate of seven per cent among adults (TACAIDS *et al.*, 2005; RAWG, 2005). Over 1.1 million children were estimated to be 'most vulnerable' in 2007, that is, over five per cent of the population of children under 18 years (MHSW, 2006). However, only four to six per cent of orphans and vulnerable children receive any external support (*ibid*).
- In the UK, an estimated 63,500 people (aged 15-59) were living with HIV in 2005 (HPA, 2006). The number of HIV affected children (those living in families where one or more members is HIV infected) in the UK has been estimated as between 15,000 to 20,000 (Conway, 2006). The global HIV pandemic continues to adversely affect black and minority ethnic populations, particularly recently arrived African migrants and refugee families, with a majority of heterosexually acquired infections acquired in Africa (68 per cent) (HPA, 2006).

Research aims and objectives

This qualitative, comparative study investigated the experiences, needs and resilience of children caring for parents/relatives with HIV/AIDS in Tanzania and the UK. It aimed to provide:

- an understanding of children's everyday experiences of unpaid care work in households affected by HIV/AIDS in Tanzania and the UK;
- the factors influencing whether they take on care-giving tasks;
- the outcomes for children and families;
- the protective factors that can reduce children's vulnerability to negative outcomes ('resilience');
- the implications for policy and practice.

Methods

Interviews were conducted with a total of 93 participants in rural and urban locations in four regions of Tanzania and in five cities/towns in England. This comprised:

- 33 children (aged under 18) and young adults (aged 18-24) with caring responsibilities
- 33 parents/relatives with HIV and guardians
- 27 service providers.

Alongside in-depth interviews, participatory methods such as photography and life story books, with sentence completion exercises, diary of a typical day and spaces for drawing, were used with children to gain insight into their caring experiences.

The majority of young people in Tanzania and the UK cared for their mother with HIV and sometimes also younger siblings with HIV in one parent households; the majority were girls. In the UK, the majority of families were African migrants, some with insecure immigration status and two of the young carers were living with HIV themselves. In Tanzania, some young people had lost both parents to AIDS.

Key findings

Despite very different socio-economic, cultural and policy contexts, children caring for parents with HIV in Tanzania and the UK share many similarities in terms of their everyday caring responsibilities, needs and aspirations. Children performed a range of caring tasks in the UK and Tanzania:

- **Household chores** - cooking; cleaning; washing dishes; laundry; shopping; (in Tanzania only) fetching water; tending livestock; cultivating crops and vegetables.
- **Health care** - reminding parent/relative to take their medication; caring for parent/relative in hospital; assisting with mobility; preparing special nutritional food.
- **Personal care** - washing/ bathing parent/relative; assisting to eat, dress and use the toilet.
- **Child care** - bathing siblings; supervising and accompanying them to/from school.
- **Income generation activities** (in Tanzania only) – begging; casual farm work; selling produce; domestic work; working in a shop.
- **Emotional and practical support** - talking and comforting parent/relative; helping to remember appointments and bills.



Figure 3: ‘This is me giving my mum porridge. I feel sad. Here I am giving my mum a shower. These are pictures of me caring for my mum’ (Drawings by Magdalena, aged 15, in Tanzania, who cared for her mother until she died).

Children and parents reported negative effects of their caregiving on children’s emotional wellbeing, health, school attendance and academic performance, engagement in leisure and social activities with their peers, relationships with family members and others in the wider community. However, many children also felt they had gained from their caring responsibilities in terms of closer relationships with their parent/relative with HIV, siblings and other family members and felt that they had become more independent, mature and had developed greater emotional resilience and knowledge and understanding about HIV/AIDS.

The study identifies the risk and protective factors that influence whether children take on caring roles and the level of their involvement in care work in families affected by HIV/AIDS. A complex range of factors at the different levels of the individual child, household, community, socio-cultural and national policy context and the global policy environment structure the context in which young caregiving takes place.

Support networks within the family, school and wider community play a significant role in building children and families’ resilience and mitigating the negative impacts of young caregiving and HIV/AIDS on households. However, in severely affected communities in Tanzania, as in many other African countries, these support networks are overstretched and the capacity of families and communities to support households affected by HIV/AIDS has been seriously diminished. In the UK and other high income countries, families affected by HIV may not have access to extended family networks or social networks in their community due to geographical distance, migration and stigma. NGOs and formal safety nets, however, provide much needed material and emotional resources for children and families affected by HIV/AIDS, although their capacity to meet the specific needs of young carers and parents with HIV is currently very limited.

Messages for policy and practice

- There is a need for greater recognition of children’s caring responsibilities in families affected by HIV from the local to the global level, and the development of policies, services and support to meet the specific needs of this group of young

carers, within the broader category of children affected by HIV/AIDS/ orphans and vulnerable children.

- Key approaches that promote resilience include practical and emotional support for parents with HIV, holistic family approaches, opportunities for short breaks, social activities with other young people in similar situations and the development of life skills. Confidentiality, cultural appropriateness and sensitivity to stigma and diverse, complex needs are paramount to the development of services for children and parents with HIV.
- Linked to this is a need for greater awareness and knowledge of HIV/AIDS within families, communities, schools, governmental and civil society organisations and welfare institutions. This would reduce stigma and discrimination, enable children and parents to seek support and help to prevent and alleviate children's unpaid care work in families affected by HIV/AIDS.

Acknowledgments

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New study highlights shared burden of young carers in the UK and Tanzania

21 September 2007

PA185/07

It's not just distance that separates the children of Tanzania and the UK. Their lifestyles, aspirations and access to employment, education and healthcare are worlds apart.

But if you are a young person looking after a parent or relative with HIV or AIDS, you might find that the differences are far less pronounced. A new study, led by Professor Saul Becker, Director of Research, and Dr Ruth Evans, both of the School of Sociology and Social Policy at the University of Nottingham, has found startling similarities between children who care for relatives in the UK and Tanzania. The research suggests that the most vulnerable often slip through the gaps of services even when — as in the UK — there are established support and healthcare systems available to them.

Despite very different socio-economic, cultural and policy contexts, children caring for parents or relatives with HIV or AIDS in both Tanzania and the UK share many caring responsibilities, needs and aspirations. Children in both countries routinely perform a range of caring tasks, including:

- Household chores — cooking, cleaning, laundry, shopping
- Healthcare — reminding the parent or relative to take medication, caring for them in and outside hospital, assisting with mobility, preparing special food
- Personal care — washing and bathing, assisting parents to eat, dress and use the toilet
- Childcare — looking after siblings
- Emotional and practical support — talking to and comforting the parent or relative, helping them to remember appointments and pay bills

Professor Becker said: "The findings are challenging for policy makers and service providers in the sense that there are huge similarities in the experiences of young carers in the UK and developing countries. In the UK we have an established and respected national healthcare system, but the stigma attached to HIV and AIDS and the difficulty in finding and then accessing appropriate services means that young carers in the UK and Tanzania have far more in common than we previously might have suspected."

The study found that in addition to these shared responsibilities, young carers living in poverty in Tanzania had the added responsibility of income generation. This ranged from begging and casual farm work to domestic work or working in a shop. They also had extra household chores, such as fetching water, tending livestock and cultivating crops.

The study, *Hidden young carers: the experience, needs and resilience of children caring for parents/relatives with HIV/AIDS in Tanzania and the UK*, explored unpaid care work by young people in the two countries. A total of 93 people — including children under 18 and young adults aged 18 to 24 that were carers, their parents and relatives with HIV or AIDS and service providers — were interviewed. They came from rural and urban locations across four regions in Tanzania and in five English towns and cities. The study was funded by the Economic and Social Research Council.

All participants were interviewed in depth, and many of the young carers also took part in participatory child-friendly research approaches — including life story books, with sentence completion exercises, daily diaries and spaces for drawing, and photography. These books and images were then used to supplement the interviews and gain a unique insight into the young carer's everyday life, experiences, feelings and aspirations for the future.

“Interviews are a trusted and effective method of getting very sensitive information about the situation of young carers and their families from all those involved,” Dr Evans added. “But they can often be difficult, particularly for children who are already in a stressful situation. By using the photographs and life story books we can look at what's important for these young people in their own terms, and at the way they deal with adversity in their everyday life, as well as how they cope with it.

“Participants were given cameras to take pictures of items, people or anything that was important to them, and many of these showed family and friends — illustrating the support networks that they call upon to help them deal with their role as a carer.”

The study also revealed the positive aspects of what would generally be perceived as a negative situation for a young person to grow up in. From increased maturity, confidence and coping skills, to strong bonds with the parent or relative being cared for, other family, community and religious groups.

“Previous studies have concentrated on the negative aspects of young carers' lives,” said Professor Becker. “This one highlights the protective factors. One of the strongest here is the relationship that the young carer has with the parent or relative. Parents are giving guidance, support, strong moral leadership and discipline — all positive factors which help to develop children's resilience.”

It is hoped that these findings will inform future research and policy developments aimed at improving the lives of young carers and their parents and relatives internationally. The interview transcripts from the study and life story books have now been deposited in the UK Data Archive, so that other researchers can draw on the original data for their own analysis.

The study outlines the need for greater recognition of children's caring roles within families, the need for greater awareness and knowledge of HIV and AIDS across societies and the promotion of resilience in families where young people are carers. These protective factors operate on a number of different levels, including that of the individual child, the household, community, socio-cultural and policy levels. Approaches that promote resilience include respite breaks, development of life skills in the young carers, practical and emotional support for parents with HIV or AIDS, social activities with other young people in similar situations, as well as developing formal and informal support networks within families, schools and the wider community.

An executive summary, Hidden young carers: the experience, needs and resilience of children caring for parents/relatives with HIV and AIDS in Tanzania and the UK is available from Professor Becker. A book, Children caring for parents with HIV and Aids: global issues and policy responses, will be published in late 2008.

Notes to editors: The University of Nottingham is Britain's University of the Year (The Times Higher Awards 2006). It undertakes world-changing research, provides innovative teaching and a student experience of the highest quality. Ranked by Newsweek in the world's Top 75 universities, its academics have won two Nobel Prizes since 2003. The University is an international institution with campuses in the United Kingdom, Malaysia and China.

This ESRC-funded study is part of a programme of research on young and adult carers being conducted in the School of Sociology and Social Policy under the leadership of Professor Becker. Other current work includes national evaluations of two Comic Relief Young Carers' Grants Programmes; the first study of young adult carers aged 18-24 in the UK funded by the Princess Royal Trust for Carers; a study of adult carers' assessments for Coventry Community Services; and three new doctoral studies funded by the ESRC and Princess Royal Trust for Carers on 'young carers in education', 'young carers in Zimbabwe' and a study of 'what works for adult carers'.

Print



Interview schedule for children and young people

1. Family background

- Can you tell me a bit about yourself?
- Who do you live with?
- Have you always lived with them? Who did you used to live with?
- Who do you help to look after at home/ did you used to look after at home?

2. Experiences of caring

- Can you tell me about a typical day and the different kinds of things you do and how you help your family? How do you feel about doing these things?
- Do you always help your family like this, or do you sometimes have more or less to do? Why do you sometimes have to help more?
- How old were you when you first started looking after....(parent/relative, younger brothers and sisters)? Why did you first start caring for? What happened just before you first starting caring for?
- Do you have particular responsibilities that your other brothers/sisters don't have? Why do you think these are your responsibilities? How do you feel about your extra responsibilities at home? Do you think your parent/relative's expectations of you are fair?
- Did your parent's/ relatives' expectations of you and your responsibilities change as you got older?
- What's the best thing about caring for(parent/relative, younger brothers and sisters)? What's the worst thing?
- How do you get on with(parent/relative)? Do you think your relationship with them has changed since you have been caring for them? (closer/more distant/ easier or more difficult)
- How do you get on with your brothers/sisters/ other family members? Has this changed since you have taken on more responsibilities at home/ person became more ill?
- Do you think you've changed since you've been helping to look after? How have you changed?

3. Impacts of caring and protective factors

Home

- What do you like about home? What don't you like about home?
- Who do you talk to if you have a problem or are worried or upset about something?
- Who can you talk to about your (parent/relative)'s illness and how you help them?
- When(parent/relative) is ill, who do you ask for help?
- Does anyone else help you care for(parent/relative)? How do they help you? How often?
- Do you have any relatives who live nearby? How often do you see them?

- What would happen if you didn't help your (parent/relative)?
- What would make things easier for you?

School/ college/ work

- What year are you in at school/ college or have you finished college? Are you working now? What kind of work do you do?
- What do you like best about school/ college? Why?
- What don't you like about school/ college? Why?
- Do you find anything difficult about school? What makes it difficult for you to go to school? What makes it difficult for you to do your homework?
- Do your teachers know about your extra responsibilities at home/ your parent/relative's illness? How do they help you?
- If you have a problem or are worried about something at school, who can you ask for help?
- Do you think your parent/relative's illness affects/ affected how you do/ did at school/ how often you go to school?
- How would you like teachers to help you?

Friends and local community

- Who are your best friends? Where do you usually see them (school, home, friend's house, church/ mosque, children and young people's club/ project, community centre etc.)
- Can you talk to your friends about(parent/relative)'s illness and the ways you help at home? Do you know other children and young people like you, who help to look after someone who is ill in the family? How do you think things are different for them than for you?
- What do you like doing when you're not in school? What don't you like doing when you're not in school?
- Do you do any paid work to earn money to help your family? Have you ever worked to earn money for your family?
- What things do you like about where you live? Why?
- What things don't you like about where you live? Why?

BREAK here?

4. Professional support

- How does(project worker) help you? How do you get on with them? What do you like about the help they give you? Can you talk to them about your parent/relative's illness and how you help your family?
- How does (project worker) help your (parent/relative/ younger sibling)? How often? Do you feel they listen to you and your (parent/relative)?
- When did the project worker first start helping you and your family? How did you hear about them?
- What do you like best about the children and young people's club/ activities they offer? Do you think you have changed since you first started going to the club/ since the project first started helping you? How?

- What don't you like about the help they give/ activities they organise? Is there anything you think they should do differently/ any ways they could make the project better?
- Can you tell me about other help you get from other services eg health, social services, school, any other organisations? How do these help you or your family?

5. Needs and aspirations

- What would make everything a bit better for you? What would make things better for your (parent/relative)?
- What do you think are the needs of children and young people who help to care for someone who is ill in the family?
- What do you want to do when you're older? What do you think you'll be doing when you're a year older? What are your priorities for the future?
- Is there anything else you want to add?

Thank you very much.

This is to say thank you, but I am not able to carry on helping your family. If you need any advice or help, please speak to:.....

I would also like to talk to a project worker who helped you and your family about the help and support that they give to children and families. Anything they say to me in the interview will be kept private. Do you mind if I talk to someone from[organisation] or any other project worker about your situation and the way they have helped you? Who would you like me to talk to about the help that you have received?

Interview schedule for parents/ relatives/ guardians

1. Family background

- Can you tell me a bit about yourself? (age, gender, ethnicity, occupation etc.)
- Can you tell me about your family? Who do you live with? (children - ages and gender - and other adults - ages, gender, occupations - living in household)
- Have you always lived here/ with ...? Who did you used to live with?
- I understand that your child has extra responsibilities at home and helps you/ when they are ill . is that right? Did your child used to help anyone else in the family previously?

2. Experiences of caring

Children's everyday experiences of care work

- Can you tell me about a typical day at home and how your child helps you/ your family? (What kind of tasks? How often per day/week?)

Factors influencing whether and why children take on caring roles

- In your culture, what do parents/ relatives generally expect of girls and boys?
- What do expect from your children? Do you feel that ...(name of child) has more responsibilities than his/her brothers/sisters? Why do you think this is?
- How old was your child when he/she first started taking on more responsibilities at home?
- Why did he/she start helping out more at home then ...? (key turning points?) What happened immediately before he/she first starting caring for ...?
- Did your expectations of your child and their responsibilities change as he/she got older? How?

Caring relationships within families

- Can you tell me a little bit about your story and what things are like for you, day to day and when you're ill/ when your relative is ill? (period of time of living with HIV, how often they get ill, emotional wellbeing, other issues and concerns etc.)
- How do you feel about your child taking on extra responsibilities and helping you/ your family? What are the good things about your child helping the family? What do you find difficult/ what is not so good about it?
- Do you think your child has changed since he/she has been helping to look after? How?
- How do you/ ...(relative who is ill) get on with your child? Do you think your relationship with ...(child) has changed since they have taken on more responsibilities at home? (closer/more distant/ easier or more difficult)
- How do you think he/she gets on with his/her brothers/sisters/ other family members? Has this changed since he/she has taken on more responsibilities at home/ relative became more ill?

3. Impacts of caring for children and protective factors

Home and family support

- When you're ill/ your relative is ill, who can you ask for help? (family members/ friends/ neighbours, project worker/ volunteer/ someone from church/ mosque/ temple etc.) How do they help you? How often?
- Do you have any relatives who live nearby? How often do you see them? Do they help you?
- Who can you talk to about your illness/ relative's illness? Do you know other people with HIV/ families in similar situations in your neighbourhood? How is their situation similar or different to yours?
- What would make things easier for you?

School/ college/ work

- How do your children get on at school/ college or has he/she finished college? What does he/she like best about school? Does he/she find anything difficult about school?
- Has your child had any problems at school (bullying, missing school, not doing homework etc.)? If he/she has a problem or is worried about something at school, who can he/she ask for help?
- Do his/her teachers know about his/her extra responsibilities at home/ your /relative.s illness? Do you find them understanding/ helpful?
- How do they help? In what ways do you think they could help you and your children more?

Friends and local community

- What things do you like about where you live? Why? Do you know many people in this area?
- What things don't you like about where you live? Why?
- What does your child like doing in his/her free time? (Play and leisure opportunities/ youth clubs etc.) What doesn't he/she like doing?
- Does your child do any paid work to earn money to help the family? Has he/she ever worked to earn money for the family?

5. Formal/ professional support

- How does ...(project worker from) help you? How often?
- When did they first start helping you and your family? How did you hear about them?
- How do you get on with(project worker)? What do you like about the help they give you? Can you talk to them about your/ your relative's illness and the help you need? Do you feel they listen to you?
- What do you like best about the services they offer? Do you think you have changed since the project first started helping you and your family? How?
- How does ... (project worker) help your children, particularly ...(name of child)? Do you feel they listen to him/her?

- Do you feel that these services and activities have made a difference to your children? (have you noticed any changes?)
- What don't you like about the help they give/ activities they organise? Is there anything you think they should do differently/ any ways they could make the project better?
- Can you tell me about any other help you get from other services eg health, social services, school, faith-based organisations, community organisations, family centres, counselling etc.? How do these help you or your family?

6. Needs and aspirations

- What would make everything a bit easier for you? What would make things better for your children/ relatives?
- What do you think are the needs of children and families in your situation?
- How does government, health, education, voluntary and community organisations/ NGOs, faith-based organisations support children and families affected by HIV/AIDS? What should they do?
- How do you feel about your situation now? What you see as most important for you and your family in the future? What are your priorities?
- . Is there anything you would like to add?

Thank you very much.

I would also like to talk to a project worker who have helped you and your family about the help and support that they give to children and families. Anything they say to me in the interview will be kept private. Do you mind if I talk to someone from[organisation] or any other project worker about your situation and the way they have helped you? Who would you like me to talk to about the help that you have received?

Are you happy for me to talk to your child alone, if he/she agrees? Where would be the best place for me to talk to your child?

Service provider interview schedule

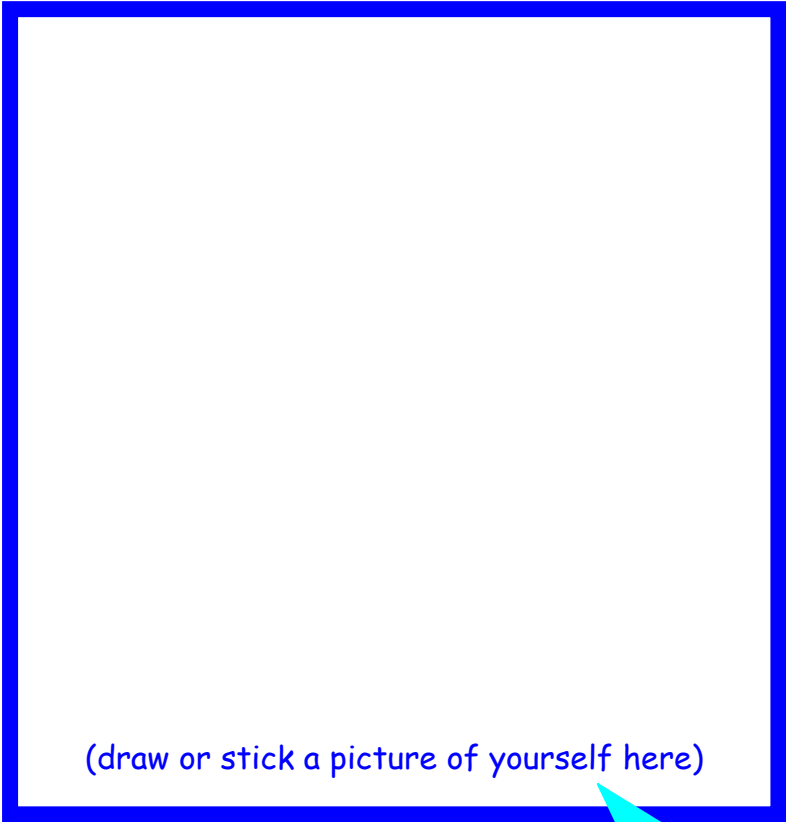
1. In what ways has your work brought you into contact with children caring for parents/relatives with HIV/AIDS?
2. When and how did they first come to your attention?
3. What support/ services do you offer to children caring for parents/relatives with HIV/AIDS?
4. Are these services targeted specifically towards children who have caring responsibilities, or are these services provided to the wider group of orphans and vulnerable children / children affected by HIV/AIDS?
5. What factors do you think influence whether and why children take on caring responsibilities, based on your experience with families in this situation?
6. In(child)'s case, which factors do you think influence whether and why they have taken on caring responsibilities?
7. What do you consider to be the positive and negative impacts of children's caring responsibilities for children caring for parents/relatives with HIV/AIDS?
8. What positive and negative impacts have there been for and their family?
9. What factors do you think help to reduce the vulnerability of children who care for a family member with HIV/AIDS and promote their resilience? (children's strategies for dealing with adversity, help and support they draw on within the family, school and wider community etc.).
10. Which factors have helped to reduce the vulnerability of and promote his/her resilience?
11. In your view, how do the experiences of children caring for parents/relatives with HIV/AIDS differ from those of children caring for parents/relatives with other physical or mental illnesses/ impairments?
12. In your view, what are the needs and requirements for support of children caring for parents/relatives with HIV/AIDS? (do these support needs differ according to age/gender etc.?)
13. How do you think the needs of children who care for a family member with HIV/AIDS differ from the needs of children living in families affected by HIV/AIDS?

Policy and practice

14. What services are children and families affected by HIV/AIDS currently able to access in this area? (statutory and voluntary and community sectors)
15. Are any of these services specifically targeted towards children caring for parents/relatives with HIV/AIDS?
16. What services are young carers in general currently able to access in this area?
17. In your view, to what extent are young carers services in contact with or supporting children caring for parents/relatives with HIV/AIDS?
18. Can you tell me more specifically about the support and services you have provided to and her/his family?
19. What is the main aim/ rationale for the strategies and practices you adopt in your work with children and families affected by HIV/AIDS/ young carers?
20. What is your professional approach towards the issue of young caring – do you aim to prevent children being drawn into caring roles, or do you respond to children's support needs once they have already become carers?
21. What is your professional approach towards the issue of disclosing the HIV status of a family member to children who are caring for a parent/relative with HIV/AIDS? What are the implications of this a) for the children and young people and b) in terms of the services you provide?
22. Which approaches and practices have you found most effective in reducing negative impacts of children's caring responsibilities, building on families' strengths and enhancing their resilience?
23. Which factors influence whether and why children and families affected by HIV/AIDS take up services, in your view? (eg. stigma of HIV/AIDS, whether child knows about parental HIV status etc.)
24. In what ways can services targeted towards children caring for parents/relatives with HIV/AIDS and their families be improved?
25. What do you see as the main barriers to the development of these services/ practices in the future?
26. In your view, what should be the roles of the statutory/ voluntary and community sectors/ faith-based organisations and those involved in informal caring in meeting the needs of children caring for parents/relatives with HIV/AIDS and their families?

Is there anything you want to add?

My story



(draw or stick a picture of yourself here)

My name is.....
.....
I'myears old

Please can you help us!

We would like you to fill in this folder to tell us about your life, your family and what you do at home. You can write, draw, stick in photos or pictures. You can do it on your own, or ask someone at home to help you. You can complete as much or as little as you like! We will take a copy of the pages you have completed and then give it back to you to keep. Thanks for helping us!

Me and my family



I havebrothers andsisters.

I live with

.....

.....

I help to care forwhen he/she is ill.

If you have pictures of your family, you could put them in here.

Me and my family



If you like drawing, you could draw a picture to show yourself and the person you care for.

Important things that have happened in my life

Here, you can draw or write about your memories of important things that have happened to you or your family. How did you feel at the time? You can also stick in pictures of people or places that are important to you.

.....

.....

.....

.....

.....

.....

.....

A typical day...

Here, you can record the things you do at home on a typical day to help your family. You can also put a sticker in the box next to each thing you do to show how you feel about this!

Here is an example:

Time	What I do	How I feel
7 am	I get up and help my brother and sister get ready for school	Sleepy
8 am	I help mum to remember to take her medicine. We eat breakfast and go to school, etc.	OK

Write the things you do at home each day and how you feel about them here:

Time of day	What I do	How I feel

My friends and the things I like doing



My best friends are

I usually see them at (please tick one or more of the following):

- school
- home
- church/ mosque/ temple
- children and young people's club
- community centre

.....

.....

What do you like doing in your free time/ when you're not in school?

I like

I don't like.....

My school



I am in class/ year...../ I have finished school and now I.....

.....

The thing I like best about school is.....

because.....

.....

The thing I hate about school is.....

because.....

.....

If you have a problem or are worried about something at school, who do you ask for help?

.....

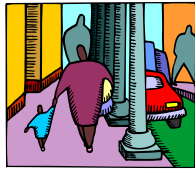
How do your teachers help you?

.....

How could teachers help you more?

.....

Where I live



I live in(name of neighbourhood, town/ city).

The things I like about living here are.....

.....

The things I don't like about living here are.....

.....

You could draw a map to show the places you go to in your local area or take some photographs of places that are important to you.

You could show us:

- the things you do every day
- the different ways you help your family
- where you go to have fun and spend time with friends
- where you go to get things you need
- where you feel safe
- where you go or what you do when you're unhappy.

What helps me?

If I have a problem or am worried or upset about something, I talk to

.....

When the person I care for is ill, I ask for help from.....

.....

Does anyone else usually help you? (tick one or more)

Someone else in the family who lives with you.....

Relative who lives nearby.....

Friend.....

Neighbour.....

Project worker/ volunteer.....

Teacher/ headteacher.....

Someone from church/ mosque.....

How do they help you?

.....

.....

.....

What would make things easier for you?

.....

.....

.....

What I want to do when I'm older

What do you think you'll be doing when you are a year older?

.....

What do you want to do in the future?

.....

.....

You could draw a picture of how you see yourself in future and the things that are important to you when you're older.

