

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' (Sevenhuijsen, 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.

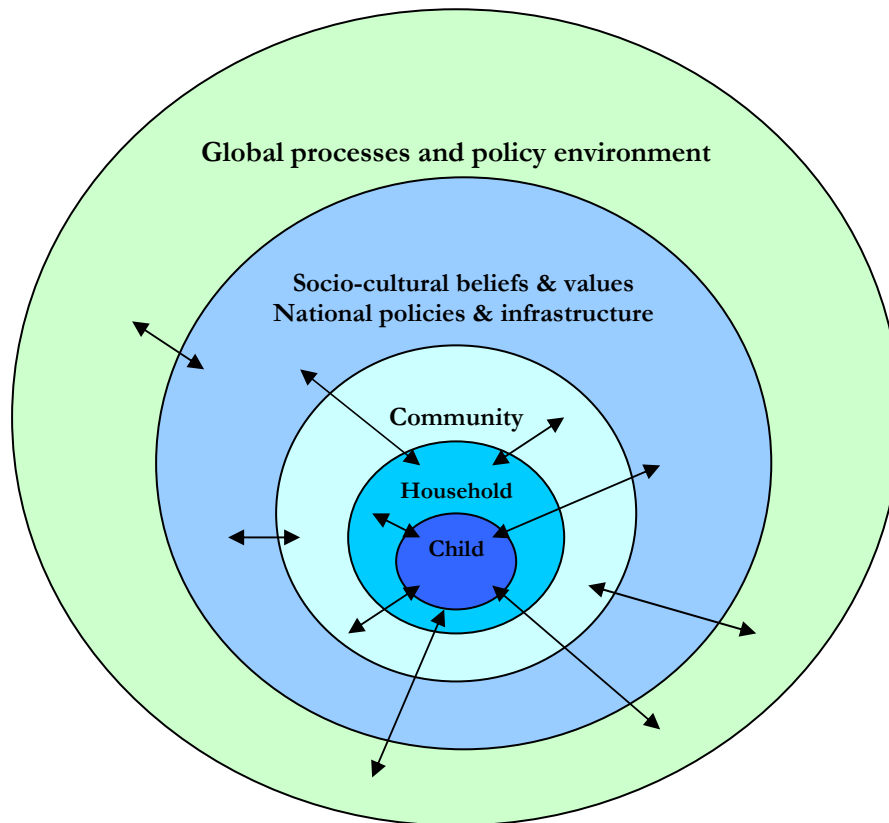
Factors influencing whether children become carers in families affected by HIV/AIDS

Developing Becker *et al.*'s (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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