

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.

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The findings of this research are discussed at length in the forthcoming book, *Children Caring for Parents with HIV/AIDS: Global Issues and Policy Responses*, by Ruth Evans and Saul Becker, due to be published in 2008 by The Policy Press, Bristol, UK. Website: www.policypress.org.uk.

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